

The continued impact of COVID-19 on patient advocacy and support organisations: findings from the second GLCC members survey

Patient advocacy and support organisations like the members of the Global Lung Cancer Coalition (GLCC) support thousands of patients worldwide. Our members are continuing to work incredibly hard to offer advice and support to lung cancer patients through the COVID-19 pandemic, a time when the virus has been the primary focus for health systems around the world. It is essential that policymakers recognise the critical role that patient organisations play in supporting patients every day, but particularly in difficult times like these.

In February 2021, almost a year after the first lockdowns were announced in most countries, the GLCC shared a survey with members to understand how the pandemic has affected organisations and the support they offer to patients. We wanted to find out if members' experiences had changed since our first COVID-19 member survey, which was conducted at the start of the pandemic in April 2020. The survey was open for eight weeks between February and March 2021.

19 organisations from 18 countries responded: Australia, Argentina, Bulgaria, Canada, Denmark, Ireland, Italy, Japan, Mexico, Peru, Portugal, South Africa, Spain, Sweden, The Netherlands, Taiwan, UK and USA.

Below are the headline findings from the survey. There were 19 responses to the survey overall, but not every organisation answered each question. The number of responses (n) to each specific question has therefore been noted in brackets. A comparison of the headline findings from our first COVID-19 survey is also included.

Demand

- Almost two-thirds of organisations (12, 63%) had seen an increase in the number of requests from lung cancer patients throughout the pandemic. Two organisations (11%) had seen a decrease whilst five (26%) had seen little to no change. (n=19)
- Of the 12 organisations who had seen an increase, seven (58%) stated the number of requests from patients was between 20% to 80% higher now than at the start of the pandemic. Two organisations stated the number of requests was lower now compared to the start of the pandemic, and three organisations (25%) did not know. (n=12)
- Most requests from patients were via telephone/helplines or email. Facebook was the social media channel through which most requests were sent; however, three organisations also frequently receive requests via Twitter. (n=19)

Most patient organisations have continued to see the number of patient requests increase throughout the pandemic

Patients most frequently send requests via telephone/helpline or email

Facebook is still the most common social media channel for patients to use, with some organisations also receiving requests via Twitter

Need

- Almost two-thirds of organisations (12, 63%) stated that the types of requests from patients have changed throughout the pandemic. In the early phase of the pandemic patients were most likely to ask about their risk of contracting COVID-19 and how to protect themselves. A year on, patients are now asking for information on the availability and safety of the COVID-19 vaccine, and the impact of COVID-19 on treatment now and in the future. Three organisations (16%) stated that requests have not changed and four (21%) did not know. (n=19)
- According to respondents to this survey, patients most frequently asked for information on the implications of treatment delays because of COVID-19 (14, 74%), advice for dealing with lung cancer diagnosis, symptoms, treatment and/or treatment related side effects (10, 53%) and information on the risk of contracting COVID-19 (9, 47%). (n=19)

Since the first survey was shared in 2020, COVID-19 vaccines have been developed and approved for use. Lung cancer patients are now frequently asking for information on COVID-19 vaccines

Patients continue to ask for information on implications of treatment delays and risk of contracting COVID-19, as well as advice for dealing with lung cancer diagnosis, symptoms, treatment and/or treatment related side effects

Services

- Over three-quarters of organisations (15, 79%) believe the pandemic has restricted the diagnosis, treatment and care of lung cancer in their country. (n=19)
- Many organisations closed services such as face-to-face advice, information hubs at hospitals, and home visits, at the start of the pandemic. Whilst six organisations (32%) stated that these services have remained closed throughout the pandemic, five organisations (26%) stated face-to-face services have started to reopen. Seven organisations (37%) did not close any services. (n=19)
- In addition, almost all organisations (18, 95%) have continued to offer patients the new services introduced at the start of the pandemic, including hosting online webinars, uploading information to their websites and online emotional support groups. (n=19)

Three-quarters of organisations believe the pandemic has continued to restrict the diagnosis, treatment and care of lung cancer in their country

Patient organisations are continuing to offer patients more digital services. However, some organisations are also starting to reopen face-to-face services that closed at the start of the pandemic

Finances

- Two organisations (2/19, 11%) preferred not to say how the pandemic impacted their income. Of those who were willing to share this information, seven organisations (7/17, 41%) have seen no change to their income during the pandemic. Five organisations (5/17, 29%) have seen an increase since the start of the pandemic, two (2/17, 12%) have seen a decrease, and three (3/17, 18%) organisations who saw a decrease in income earlier in the pandemic are now seeing an increase. (n=19)

- Only Australia, Canada, the UK and the US stated that their national or regional government has offered their organisation any financial support during the pandemic. (n=19)
- 7 organisations (37%) are worried about their ability to provide the same levels of services to patients as before the COVID-19 pandemic. (n=19) Five organisations are worried about their organisation's survival (26%) and four are worried about the employment of their staff (21%). (n=19)

Some organisations are now starting to see an increase in their income, including some that saw a decrease initially

However, in many cases, national and regional governments are still not offering any financial support

Organisations remain concerned about the impact of the pandemic on their operations, but the level of concern has stayed similar, and, in some cases, has decreased

COVID-19 vaccines

- COVID-19 vaccines are available in over three-quarters (15, 79%) of responding organisations' countries. (n=19)
- All organisations stated that their country has a list of groups who will be prioritised to receive their COVID-19 vaccines. These groups include medical professionals, the elderly and those who are extremely clinically vulnerable/have chronic illnesses. (n=19)
- Bulgaria was the only country where our member responded that lung cancer patients had already been vaccinated at the time of the survey (n=19). Of the countries that have not yet vaccinated lung cancer patients, two-thirds of organisations (12/18) believe patients will be vaccinated within the next six months. Two organisations (11%) believed lung cancer patients will be vaccinated in six months to a year, and two (11%) did not know. (n=19)
- 11 organisations (58%) stated they have received queries from lung cancer patients about COVID-19 vaccines, including regarding the vaccine's safety and availability. 12 organisations (63%) have been offering patients information and advice on the COVID-19 vaccines. (n=19)

More information

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