# Impact of COVID-19: findings from a GLCC members survey (June 2020)

Patient advocacy and support organisations like the members of the Global Lung Cancer Coalition (GLCC) support thousands of patients worldwide. Our members are working incredibly hard to support lung cancer patients through the COVID-19 pandemic and, in some cases, doing this with decreased resources. 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 May 2020, a survey was sent out asking our members about their experiences through the pandemic. Questions were based on four themes: demand, need, services, and finance. 22 organisations from 21 countries and one Europe-wide organisation responded: Argentina, Australia, Bulgaria, Canada, Czech Republic, Denmark, Germany, Ireland, Israel, Italy, Mexico, the Netherlands, Peru, Portugal, Slovenia, South Africa, Spain, Sweden, Taiwan, the UK, and the USA.

It is clear from this survey, that the impact on our GLCC member organisations and the impact on lung cancer services in their country, are dependent on where the country is, in the COVID-19 cycle.

Below are the headline findings from the survey. There were 23 responses to the survey overall, but not every organisation answered each question. The number of responses (n) to a specific question has therefore been noted in brackets.

*Demand*

* Almost two-thirds of organisations (14, 64%) had received more requests from patients since the start of the pandemic. Five organisations saw a decrease; three noted little or no change (n=22)
* Most requests from patients were via the phone/helplines or email. Facebook was the social media channel through which most requests were sent; one organisation (Canada) received requests via Twitter. No organisations received requests via Instagram, but not all GLCC member organisations use every social media platform (n=16)

*Need*

* Patients wanted advice on a range of issues, most notably, the risk of contracting COVID-19 (82%, 18) and implications of treatment delays/alterations due to COVID-19 (86%, 19). Also, advice requested on shielding; travelling to appointments; implications of treatment delays; coping with a lung cancer diagnosis; managing symptoms, treatment and/or treatment related side effects; money worries; mental health; and access to personal protective equipment (n=22)

*Services*

* Most members (73%, 16) believe the pandemic has restricted the diagnosis, treatment and care of lung cancer in their country (n=22)
* Most organisations (14) have had to close services due to the pandemic, particularly face-to-face services such as support groups, community outreach programmes, seminars, mental support home visits and information hubs at hospitals (n=21)
* However, 86% of organisations (18) have introduced new services, with digital interaction replacing face-to-face services. For example, members have implemented calls to patients, provided online counselling and extended helplines. They have also set up podcasts, webinars or apps with information on COVID-19. Some have set up volunteer services to get food and medicines for patients who are shielding (n=21)

*Finances*

* Only one organisation has seen an increase in their income since the start of the pandemic. Almost half of responding organisations have seen a decrease; six organisations preferred not to say (n=21)
* Only Australia, Denmark, the UK and the US noted that their national or regional government has offered some financial support to their organisation during the pandemic (n=21)
* One quarter were worried about the future survival of their organisation. 35% of the organisations (7) are worried about their ability to provide the same level of services and employ their staff (45%, 9), as they did pre-COVID-19 pandemic (n=20)
* GLCC members were keen to know of any global or national funds that they could apply to secure income. The GLCC secretariat is sharing any intelligence it receives on this, as well as examples of good practice that could be shared

More information

Established in 2001, the GLCC comprises 40 non-government patient organisations from 29 nations: Argentina, Australia, Brazil, Bulgaria, Canada, Czech Republic, Denmark, Egypt, France, Germany, 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 the work of the GLCC please visit: [www.lungcancercoalition.org](http://www.lungcancercoalition.org) or email our secretariat at: [glcc@roycastle.org](mailto:glcc@roycastle.org)