Assessing the impact of the COVID-19 pandemic on patient advocacy and support organisations

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DISCLOSURES

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<th>Commercial Interest</th>
<th>Relationship(s)</th>
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<td>Amgen, AstraZeneca, Boehringer Ingelheim, Bristol Myers Squibb, Eli Lilly, Merck, Novartis, Pfizer, Roche, Takeda</td>
<td>The Global Lung Cancer Coalition (GLCC) has received no specific funding for this project. The GLCC receives support from a number of Sustaining Partners, commercial companies that want to demonstrate their commitment to lung cancer patients by helping the GLCC promote global understanding of the burden of lung cancer and the right of patients to effective early detection, better treatment and supportive care.</td>
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The Global Lung Cancer Coalition (GLCC) is a partnership of 40 patient organisations across 29 countries.

Our members play an essential role in supporting patients every day, and we knew they were being called on for increased support as the COVID-19 pandemic hit.

The GLCC wanted to understand the pandemic’s impact on our members, identify challenges they were experiencing, and any common themes or differences.
Methodology

A multinational steering group designed a 15 question survey.

Questions were based on four themes: demand from patients, patient needs, changes to services offered, and impact on organisation’s finances.

The online survey was sent to all GLCC members and was open for three weeks between April and May 2020.
23 responses

22 organisations from 21 countries and one pan-European organisation responded.
Key findings

Increased requests from patients via telephone, email, Facebook and website
Frequent questions on risk of contracting COVID-19 and implications of treatment delays because of COVID-19

2 in 3 responding organisations had closed face-to-face services. But 86% had introduced new online or digital services

67% of organisations have seen a decrease in their income

Only five organisations’ national or regional governments had offered any financial support to charities

Members’ worries included how to provide same level of services as pre-pandemic, how to keep employing staff, and even their survival as an organisation
Takeaway and next steps

Patient organisations are providing more support during the pandemic, and many are doing so with decreased resources.

The GLCC is planning two further surveys to understand the continuing impact of COVID-19 on patient organisations (Winter 2020 and Spring 2021).