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## Organisations for patients with cancer feel the brunt of COVID-19 pandemic



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The ongoing COVID-19 pandemic has disrupted all facets of cancer care, from delaying diagnoses and treatment to halting clinical trials and biomedical research. Patient organisations have not been spared from the impact, with all aspects of their work affected, and in some cases, their very viability.

To assess the impact of the pandemic in organisations for patients with cancer, a survey was done by a joint initiative of the World Ovarian Cancer Coalition, the World Pancreatic Cancer Coalition, the Lymphoma Coalition, the Advanced Breast Cancer Global Alliance, and the World Bladder Cancer Patient Coalitions. Responses were received from 157 member organisations located in 56 countries. Most of the responses came from the USA (28 responses) followed by Australia (ten), and then Canada, Italy, and the UK (eight each).

Overall, the findings showed that every aspect of the work done by these organisations has been affected to varying degrees by the pandemic. 89% of organisations reported that they had to change their services for patients with cancer in some way, but were experiencing an increase in calls and requests for assistance from patients with cancer. Nearly all organisations (92%) provide support services to the cancer community, and the pandemic has increased the number of people reaching out for assistance. More than half (57%) of organisations have had an increase in the number of calls and emails that they have received, with a mean increase of 44%.

But as the need for supportive services rose, the organisations increasingly found themselves having to cut back on their activities,

advocacy, and research, with some struggling just to stay afloat. Half of the organisations involved in raising awareness reported having to change their activities by cancelling or postponing events, whereas more than two-thirds (68%) involved in health professional education activities had to change their services, move materials online, or temporarily halt their programmes. Therefore, many of the organisations are struggling financially and only 5% felt that they were “confident of their financial position” during this time.

“All were concerned for their viability and our survey showed that the situation is very dire and concerning in terms of the number of organisations that might not survive”, said Clara MacKay (World Ovarian Cancer Coalition), one of the groups conducting the survey. “The pandemic has been the perfect storm in terms of its catastrophic financial impact.”

MacKay explained that most organisations raise money through fundraising events, and those were cancelled seemingly overnight. Many of the people who support charitable organisations have also faced financial uncertainty and have decreased their donations.

“Many patients rely on the services of organisations and these services have also been cut back, as this survey indicates”, said Jeremy L Warner (Vanderbilt University, Nashville, TN, USA). “I am very concerned about the financial viability of some of these organisations, large and small, and hope that there will be governmental actions to prevent insolvency, if necessary.”

Fundraising to support the organisation’s activities was practiced by nearly all survey participants, but

more than three-quarters (79%) predicted that their income will decline during the next 12 months. Across the board, every type of fundraising has been affected, including grants, major donors, online donations, and events.

The average expected decrease in income was 46%, although this decrease varied from 7% to 95%. About a fifth of groups feared that the decline in income would affect their viability, although a few organisations reported that they had actually had an increase in funding from sources that included major donors, grant providers, and pharmaceutical companies. As a result of decreased funding, 71% of organisations reported the need to review budgets and available income and over half (55%) have already had to reduce costs.

For those organisations involved in research, 30% reported concern about the viability of their current projects, and only 48% expect to be able to resume funding or their research when the pandemic is over. Key issues that affected research were continuing costs associated with projects, pauses in clinical trials, and repurposing of laboratories for COVID-19 research.

Issues related to funding was the most prominent concern, followed by concerns about patient care and lack of direct access with patients.

Respondents also offered advice for other groups facing similar issues. One was the urgent need to embrace new technologies and explore new ways of reaching out to patients and others who could benefit from their services. Another was to boldly review plans, and to collaborate and share data and ideas.

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