COVID-19 is creating significant challenges for millions of cancer patients around the world, including delays in diagnosis and treatment – all made worse by an underlying concern about the essential safety of cancer patients during a pandemic.

Since the outset of this pandemic, patient advocacy organisations have stepped up their activities to ensure that cancer patients are not forgotten. In the face of enormous financial and organisational challenges, their tireless work to support patients has continued and indeed expanded to provide the most up to date COVID-19 advice and information. But the additional workload, together with the financial hit they have taken due to the lockdown, are now threatening the future of many of our organisations and the services they provide.

To help us better meet the challenges we are facing, a group of global cancer coalitions and alliances have been collaborating to share our COVID-19 insights and experiences and get our voices heard. A survey we conducted of 157 cancer patient organisations supporting over 350,000 patients from 56 countries showed a collapse of their finances coupled with a huge increase in demand for their services that is unsustainable. We are now calling for governments to recognise the huge value of the work these organisations do, as voluntary groups, and to provide urgent support to help them survive the pandemic and play their role in helping our patient communities through this difficult time. And we are asking the cancer community as a whole to support and amplify that call.

How bad is it?

Our survey on 'The Impact of COVID-19 on Cancer Patient Organisations' was developed and conducted by the World Ovarian Cancer Coalition in collaboration with the World Pancreatic Cancer Coalition, the Lymphoma Coalition, the World Bladder Cancer Patient Coalition and the Advanced Breast Cancer Global Alliance. It aimed to quantify and document the experiences of our member organisations.

While we were confident that the results of the survey would make for discouraging reading we were not prepared for just how grim the results would be. The findings highlighted a serious and dangerous collateral effect of COVID-19 – jeopardising vital services and indeed the very existence of many patient organisations at a time when their services are needed most.

Many are at breaking point and need immediate financial support to survive. With disappearing resources, organisations are working as quickly as possible to adapt to the changing landscape and to develop new and innovative platforms to provide crucial services and activities. Their breath-taking flexibility and resilience underscores their commitment to the patients they serve. Despite overwhelming circumstances, they are keen to learn and collaborate.

How their work has changed

Almost all organisations have had to alter their services (89%). Most have had to produce new information relating to COVID-19, half have had to move services online, and a third have developed new services. The majority have seen large increases in calls, often about COVID-19, fear of catching the virus, and the impact on cancer treatment.

They have had to radically alter their awareness-raising activities, health professional education and advocacy programmes. For those who fund research, a third are already concerned about the viability of their current projects, and a further 39% are fearful that they will be impacted.

The financial cliff

Only 5% are confident of their financial position. Eight in ten are predicting a fall in income over the next twelve months, and the average expected drop is a staggering 46%. Every aspect of their fundraising has been affected, not just community or organisational fundraisers, but support from pharmaceutical companies, major donors and trusts. They are having to make staff redundant and rip up existing business plans in the face of dramatically reduced income at the same time as getting to grips with remote working, and upskilling volunteers and employees to deliver new online services.

Patient organisations WILL disappear without support

These findings point to an urgent need to support the very organisations that for so long have played such an important role supporting cancer patients, advocating for positive change in cancer policy and practices and raising funds for vital research. The societal and economic value of this contribution should not be under-estimated – its loss would be immeasurable.

We urge all of those with an interest in cancer to get behind local and national patient organisations. Governments are moving to bolster economies and industries – these measures must be extended to patient advocacy groups to ensure that they are not victims of COVID-19.

Our survey gave participants the opportunity to share their trials and tribulations, but also their advice: ‘Be nimble’, ‘Don’t give up’, ‘Embrace new technologies’, ‘Learn from each other’, ‘Try to look to the long term’.

One group from Barbados said, “Keep in touch with your patients. They are fearful and so are we, but we offer a service and, until we can no longer deliver that service, we must be the light that shines for them.”

We need your help so their lights will continue to shine.

World Bladder Cancer Patient COALITION

For the full results of the survey on 'The Impact of COVID-19 on Cancer Patient Organisations'can be found here

Clara MacKay is Executive Director of the World Ovarian Cancer Coalition