The Impact of COVID-19 on Cancer Patient Organisations

A joint initiative by 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 – June 2020

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Executive Summary

Covid-19 is a challenging time. Which C is the bigger one?
V Care Foundation, India

This report is the work of five global cancer patient coalitions, representing around 400 organisations. It demonstrates the enthusiasm and willingness to collaborate at a very challenging time, to develop and strengthen calls to action, to learn from each other and support those we work with and communities we serve.

Cancer patient organisations, large and small, perform vital services connecting with, supporting and advocating for, cancer patients around the world, providing essential funds for research and insight into patient experience. The COVID-19 global pandemic has quite literally wreaked havoc with all of our lives, but especially for cancer patients. Often at increased risk of infection and serious illness themselves, there have been disruptions to diagnosis, surgery, treatments, trials, follow up, support and palliative care. Many have been required to 'shield' from others, totally withdrawing from life outside their homes, thus increasing the already high levels of isolation they feel because of their life-limiting conditions.

As this report shows, cancer patient organisations around the world have been a key point of contact for vulnerable people, and this has increased dramatically as COVID-19 has spread far and wide. This level of support has been achieved at a time when the organisations themselves have had to cope with relocating staff and volunteers, developing new services, acquiring new tools and skills, all whilst experiencing stark falls in income and a very uncertain future.

The quotations included in this report reflect the variety of organisations and countries involved and show that everyone has been affected significantly, no matter where they are, their size, or the type of cancer patients they support. There are many quotes, but organisations told us they wanted to hear from others facing the same situation. In total there were 157 organisations who took part, from 56 countries, supporting over 350,000 people living with mainly ovarian, gynaecological, pancreatic, gastrointestinal, bladder, advanced breast cancers, blood, lymphoma and chronic lymphocytic leukaemia (CLL). Some are in countries where COVID-19 is under control, others are at or approaching the peak of the pandemic, and some are just starting out on this journey.

The key findings in this report show that all aspects of the work of cancer patient organisations have been affected:

Support Services

- Nearly six in ten organisations who provide support services for patients have seen an increase in the number of calls and emails, with an average increase of 44%
- Seven in ten organisations have had calls relating to COVID-19, on average 35% of their total call volume
- Almost all organisations have had to alter their services for people with cancer (89%)
- Most have had to produce new information relating to COVID-19 (63%), half have moved existing services online (49%) and a third developed new services (33%)

Awareness, Education and Advocacy

- Half of all organisations raising awareness have had to alter their activities, cancelling and postponing events, and altering messages
- Almost seven in ten (68%) involved in health professional education activities have had to alter services, moving online, or pausing programmes as health professionals are redeployed
- Two-thirds of those undertaking influencing or lobbying activity have had to delay or alter their activities and messaging

Research

- Half of all the organisations who participated were involved in funding or undertaking research. Just a quarter of these activities were unaffected at present
- A third are concerned about the viability of their current projects (30%) and almost four in ten are still uncertain about this (39%)
- Three in ten organisations involved in research say they expect to reduce the amount of funding they can supply, or the amount of research they undertake in the future

Fundraising

Almost all organisations fundraise to support their activity.

- Only 5% are confident of their financial position at this time
- Eight in ten are predicting a fall in income over the next twelve months, on average a drop of 46% is expected
- Every type of fundraising is affected, from grants and major donors to direct mail, online donations, to community fundraising and organisation run events
- One in five say that drops in income are currently affecting their viability and 45% say this may be the case in the future

Organisation of Services

- One in ten organisations have made staffing cuts
- A similar proportion have ‘furloughed’ staff (a government scheme to support staff wages)
- A third have had to source technology and equipment to move the working environments into homes and a similar proportion have had to source technology and equipment to develop new services
- There are concerns about staff burnout, and the lack of direct contact with patients and colleagues

Impact on Cancer Care and Diagnosis

- Every aspect of cancer diagnosis, surgery, treatment, follow up, clinical trials and support has been affected. For some, treatment has been withdrawn altogether, for others it has been altered
- Few have established working systems to keep cancer patients well away from COVID-19 treatment centres

- Whilst most countries or local areas do have guidelines for cancer care during COVID-19, respondents said the guidelines sometimes differ region by region, or even hospital by hospital. The guidelines are not necessarily being implemented, and they can make messaging to people with cancer more confusing. There is a considerable level of anxiety amongst people with cancer about their risk of COVID-19, particularly when attending hospital, but there is a strong danger that their cancer worsens because of these fears

In conclusion, there has never been a more urgent need for the work of these vital life-supporting organisations, and for focus on what can be done to minimise the impact of COVID-19 on cancer diagnosis, treatment and support in every country. For information we have also included, with permission a summary of results of a survey of members by the Global Lung Cancer Coalition, which show very similar findings on key metrics. This can be found in the Appendix.

Our messages are clear:

- If you already support a cancer patient organisation, please continue to do so, and if you possibly can, increase that support
- To those who can enable organisations to develop technological solutions and collaborative working, your support will be vital, opening up access to patients and helping the charities survive and thrive
- It is important to learn what has worked well and take the positive aspects of this pandemic forward, but it is also vital to understand where aspects of cancer care and support are under threat and progress has been slowed
- To those who have the power or influence to ensure that cancer treatment and services are not set back several years, please listen to those organisations who can articulate clearly the impact on patients, work with them, and act on it as soon as you can

Cancer will not wait for COVID-19 to pass, if it ever will, and the patient organisations are the key to minimising the devastating impact on people with cancer.

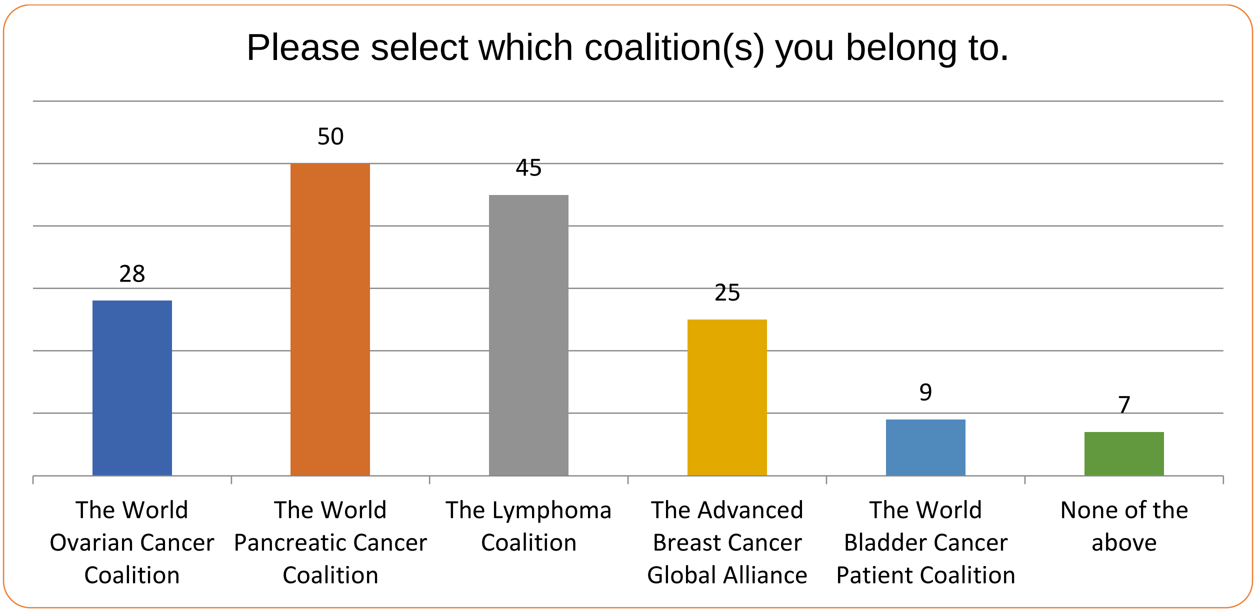
Keep in touch with your patients. They are fearful and so are we but we offer a service and, until we can no longer deliver that service we must be the light that shine for them.
The Myeloma, Lymphoma and Leukaemia Foundation of Barbados

Elisabeth Baugh, Chair, and Clara MacKay, Executive Director, **World Ovarian Cancer Coalition**
Julie Fleshman, Chair, and Jenny Isaacson, Project Lead, **World Pancreatic Cancer Coalition**
Lorna Warwick, Chief Executive Officer, **Lymphoma Coalition**
Alex Filicevas, Executive Director, **World Bladder Cancer Patient Coalition**
Fatima Cordosa, President, and Roberta Ventura, Chief Operating Officer, **Advanced Breast Cancer Global Alliance**

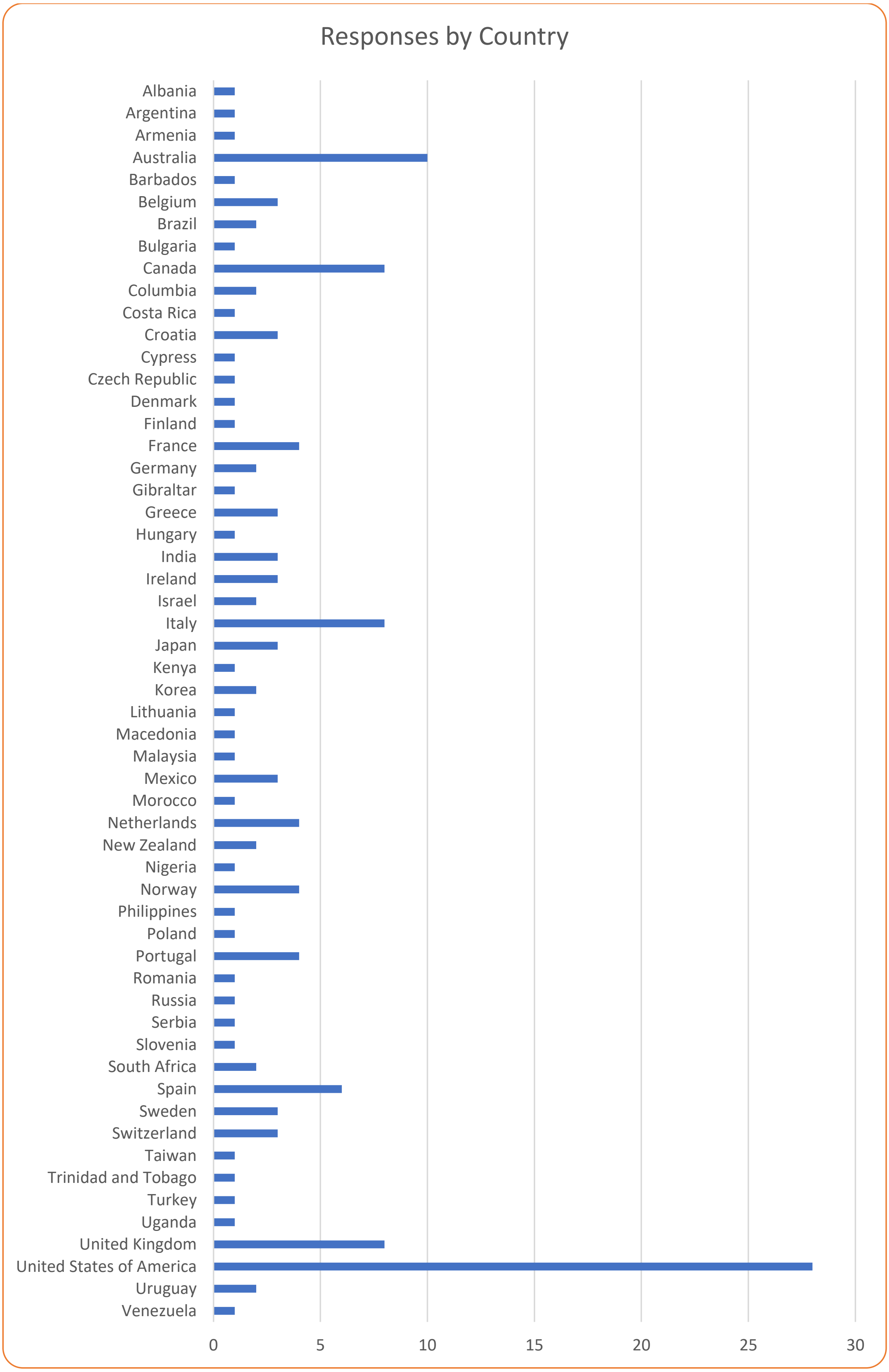
About the Organisations that Participated

A total of 157 responses have been included in this survey, from 56 different countries. The greatest number of responses received were from the United States of America (28) followed by Australia (10), Canada (8), United Kingdom (8), Italy (8) and Spain (6). The total list of countries represented is listed on the next page. The countries are all in different stages of the pandemic.

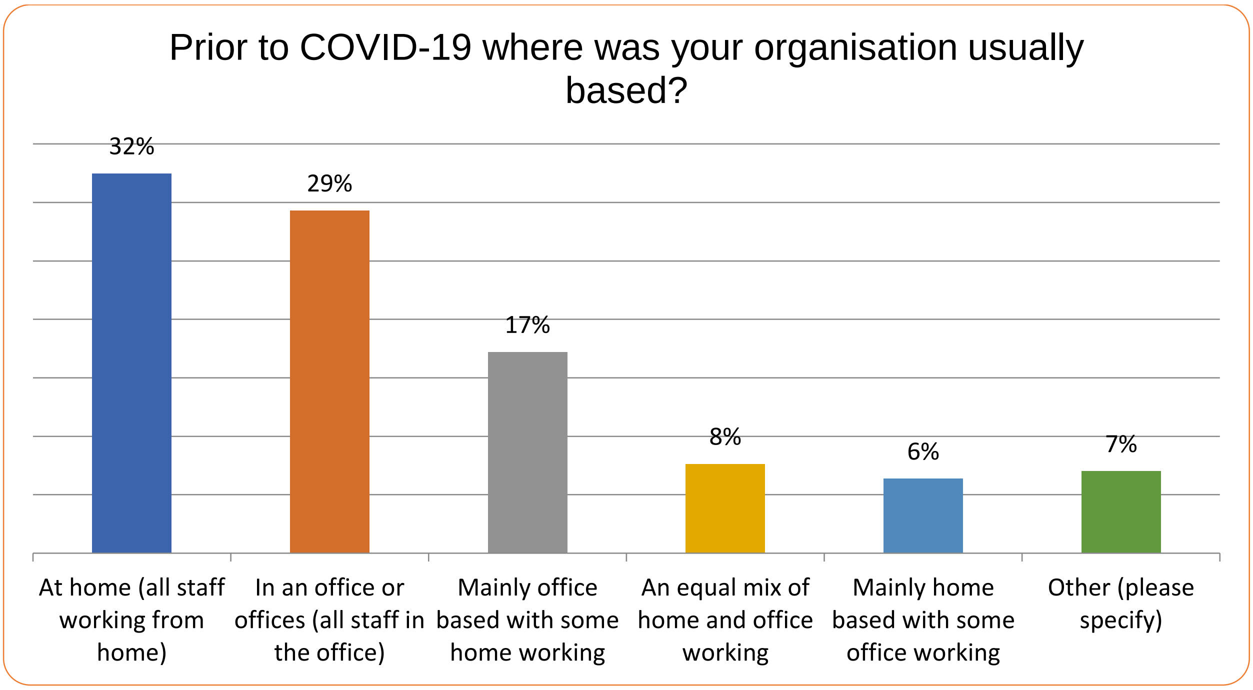
The organisations are members of the participating coalitions as follows. A few organisations are members of several coalitions, and 9% of the respondents were from organisations representing people with all types of cancer.



It is estimated that these organisations are in contact with over 350,000 people living with cancer every year.


Responses by Country
Albania
Argentina
Armenia
Australia
Barbados
Belgium
Brazil
Bulgaria
Canada
Columbia
Costa Rica
Croatia
Cypress
Czech Republic
Denmark
Finland
France
Germany
Gibraltar
Greece
Hungary
India
Ireland
Israel
Italy
Japan
Kenya
Korea
Lithuania
Macedonia
Malaysia
Mexico
Morocco
Netherlands
New Zealand
Nigeria
Norway
Philippines
Poland
Portugal
Romania
Russia
Serbia
Slovenia
South Africa
Spain
Sweden
Switzerland
Taiwan
Trinidad and Tobago
Turkey
Uganda
United Kingdom
United States of America
Uruguay
Venezuela
0
5
10
15
20
25
30

Before the outbreak of COVID-19, organisations described their working arrangements as follows:



Almost four in ten organisations have no paid staff (39%), and only 37 out of the 157 organisations have more than 5 full time equivalent employees (24%). Almost all organisations (98%) rely on volunteers to deliver their services. In total almost 17,500 such people are supporting the work of 154 organisations.

Almost all organisations have continued to operate but some of the early comments showed that the pandemic dramatically changed what they could offer:

We had a sudden lock down and we could not access office to give face to face counselling. We stopped research due to national guidelines on research. We continued giving information via phone and social media especially WhatsApp. We created groups for patients and counsellors to continue interacting. **Uganda**

The following activities are now being organised and conducted on an online platform: 1. All staff are working from home. 2. We also have skeletal staff taking turns to work in the office. 3. Upon diagnosis of patients, the hospitals' medical team seeks patient's permission to give her/his phone number to the peer counsellor and vice versa. The peer counsellor attends to the patient on the phone. Patient's information and rehabilitation pack from the peer counsellor is now being given to the patient by the medical team. 4. The monthly group counselling session is conducted on the virtual platform via Microsoft TEAMS. 5. Interactive seminars and talks by experts for those affected by breast cancer are now organised and implemented on the Microsoft TEAMS platform and they are conducted more often (weekly) than in the past. 6. Our choir lessons rehabilitation group (Pink Melody) has been using Microsoft TEAMS platform for their weekly lessons. Surprisingly attendance for every online session above is much higher than when we had face-to-face sessions. 7. Script is being prepared by our Community Outreach nurses to deliver "Early Detection" talks online. **Malaysia**

We didn't stop services we are trying to be useful for our member despite COVID 19 and earthquake in Zagreb (happened March 22 2020). Our country independence is born in war 1991 and we are used on troubles and hard times. **Croatia**

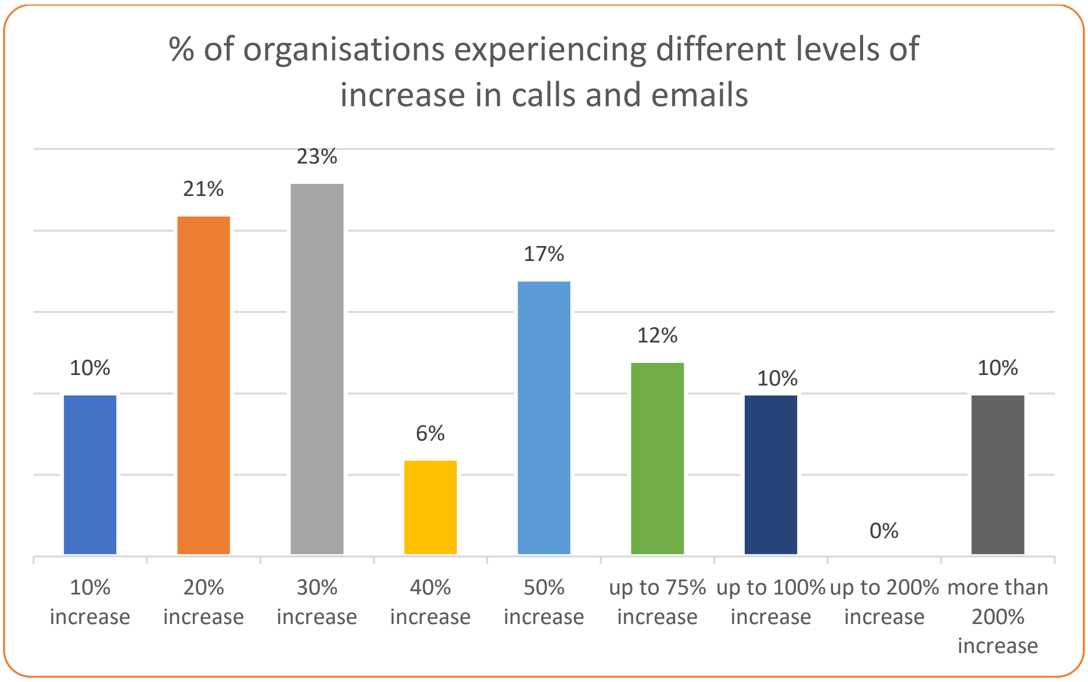
Physical meetings and gatherings were stopped. Board meetings were already virtual. The May campaign was altered to become an information campaign ("Do you know that..."[1 fact each day]) from our Facebook page. We also established a new meeting place, a virtual internet cafe. **Norway**

Just six organisations have not been able to supply any services to people with cancer. Three of these were new organisations still in the process of setting up, and one was led mainly by clinicians who had to divert their attention to clinical care.

Support Services for People with Cancer and Their Carers

Nine in ten organisations surveyed provide support services for people with cancer and their carers (92%). Of those that do, 57% say they have had an increase in the number of calls and emails, by varying amounts as the following chart shows. The average (mean) increase was 44%.

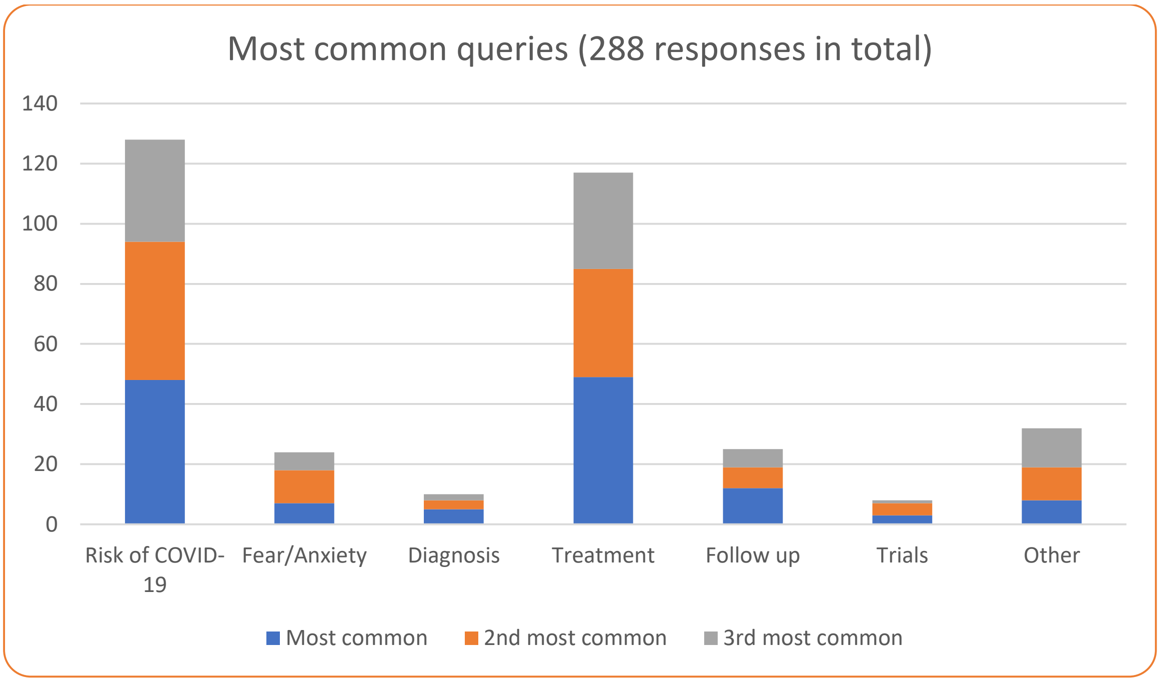
Calls and Emails



For the 69% of organisations who had calls and emails relating to COVID-19, the average highest proportion of calls relating to COVID-19 was 35% but varied from 1% to 100%.

For the 19% of organisations for whom calls and emails have decreased, the average decrease is 50%. Organisations focussing on people with breast or pancreatic cancer were twice as likely to report a drop in calls and emails (one in five), and ovarian cancer least likely (one in 15).

Organisations were asked to list the three most common queries raised by people with cancer. Questions about the risks of contracting COVID-19 and cancer treatments during the pandemic were by far the most common, accounting for 85% of all queries. Each free text answer was allocated one or more tags. The category 'other' included nine queries about finance and six about second opinions.



Services Offered

Almost all organisations have had to adjust their services (89%). Most offer support or education activities (85%, 86% respectively) but other activities can include financial assistance, accommodation for patients and caregivers travelling from rural areas, food, patient navigators and palliative care in the home.

Most have produced new information relating to COVID-19 (63%), half have moved existing services online (49%) and a third have developed new services (33%). The following quotes give a flavour of what has been done, including seizing new opportunities in these difficult times.

We have created resources for constituents including, but not limited to the following information about COVID-19: Symptoms – precautions/tips for prevention; questions to ask the healthcare team; local resources (including food pantries, Dept. of Health information for states, pharmaceutical company resources, etc.); general information on treatment impact and guideline updates; and how to locate resources. We have also offered webinars focused on navigating pancreatic cancer care during the coronavirus crisis. **USA**

Ask the Expert: We have had questions posed to Health Care Professionals and they have made a video on their phones with the answer to post on social media. Acquired more teleconference phone lines to offer to community support groups. Reaching out directly right away when someone requests a resource to make sure they received it, that they have no questions and just generally checking in more **Canada**

We developed a new program of transfers from their homes to the hospital for cancer patients in chemotherapy and radiotherapy. 200 monthly transfers. We created a virtual community instead of our face-to-face support group, we started in April and we have 108 members, virtual sessions are held every two weeks. Campaign on our social networks that provides information about cancer and COVID-19. Live broadcasts on: oncology, psycho-oncology, nutrition, physical activity, etc. We increased the number of people benefited in our "Bread of Love" program that provides food to low-income patients. **Costa Rica**

Our psychological support services (both group sessions for patients and caregivers and one-on-one sessions) take place online. Our social worker supports patients and caregivers via phone calls. Since we turned to online services, we have expanded to supporting patients and caregivers from all over Greece. Moreover we launched a new project of webinars for psychologists and social workers of other patients' associations. Finally, the seminars we were planning to raise cancer awareness via the internet. **Greece**

We started a new programme focused on using media to educate cancer patients. Online Support Group: We moved our support group meeting from face-to-face to online…..COVID19, Cancer & Telemedicine: We are currently conducting a study on telemedicine use in Nigeria. **Nigeria**

Totally revamping our educational programs to be delivered in new ways in an online format - not just replicating the in-person formats, but reaching out to our community and asking them what they would find the most valuable - we've conducted an ad hoc survey along with two online focus groups to help inform the best path forward which also investigating the best technology to use along with additional costs associated with adding new services to deliver online programs in a valuable way. **USA**

More than ever, the patient/support services should be strengthened **France**

We have seen a great acceptance of the patients to this new form of receiving support. They are grateful they don't need to take public transportation for hours, thus reducing the risk for infection. **Mexico**

We have seen a substantial increase in reach and engagement with women with ovarian cancer in the UK since the onset of Covid-19, driven by our switch to digital support services. **UK**

Seventeen percent of the organisations have conducted a patient survey relating to COVID-19, and another 14% plan on doing so. Please remember to share your results with your relevant coalition!

Symptom Awareness Activities

Almost seven in ten organisations are involved in symptom awareness activities. Most commonly this is directed at the general public, but half the organisations also undertake awareness raising with healthcare professionals such as nurses, medical students or family practitioners (53%).

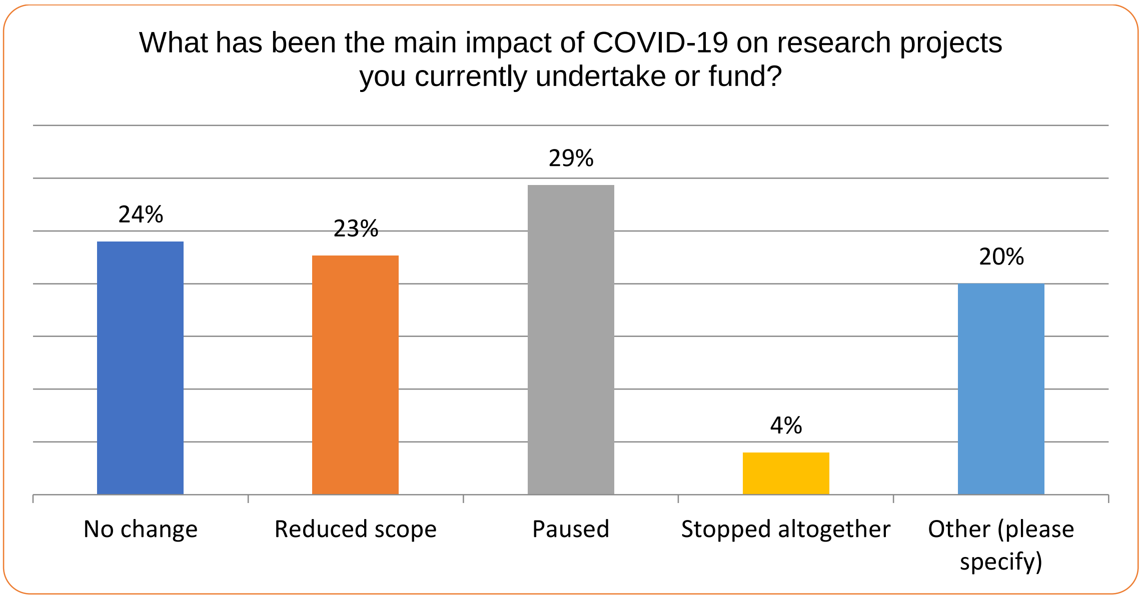
Half of the organisations who raise public awareness have had to alter their activities because of the pandemic. Many have had to cancel or postpone events because of social distancing and lockdowns. Some decided to tone down their campaign and delay in order not to overload stretched health systems. Others, having initially paused activity to focus on COVID-19, are now stepping up activity in response to the sharp fall in referrals for suspected cancer. Activities that have gone ahead have been almost all digital, either through social media, Zoom webinars or other online formats.

An even higher proportion of those providing healthcare professional education activities have had to alter their services (68%), mainly by finding online solutions. One organisation switched to a phone service but found it was not productive. Some have found however that doctors and nurses are too busy with the pandemic to participate, and that their appetite for such activity is also diminished. However, for those programmes that involve patients there have been some benefits:

We are doing the classes using Zoom. It is going well and the survivors love not having to leave their home and not having to include drive time to their time donation. **USA**

Research Activities

Just over half of the responding organisations either fund or undertake research (52%). Already there has been a significant effect on their research activities.



Almost a third of organisations are concerned about the viability of their current projects (30%), and almost four in ten are still uncertain (39%). Just under half expect to be able to resume funding or their research (48%) after the pandemic, but for nearly three in ten organisations (28%) they expect to reduce the amount of funding or activity.

Key issues include falling income despite ongoing costs associated with research, closure of some clinical trials, repurposing of research labs into COVID-19 testing centres, and concern that the lack of research and trials will put back progress in terms of treatments.

We have a small grants programme for cancer research projects. Some of this year's grants are being delayed due to clinician or nurse applicants being unable to commence their project due to Covid-19 and the impact on health services - however we are taking a very flexible approach and will fund all we can or encourage applicants to resubmit for next year (we have ring fenced budget for this research funding). **UK**

The government funding is restricted and so stable, however the research funded by our own direct donations is at risk and has been cut back significantly this year. **Canada**

Salary funding is being used up for researchers with no access to the labs but the major concern is no charities can afford to fund all those salaries again when income is down. **Ireland**

We fund a variety of research programmes, some of which have had to be paused and elements of their work delayed. Fortunately, some have been able to use this time to write papers and further their background work by meeting our lay panel of patients, the Research Involvement Network, to help inform the research etc. **UK**

All current research grant commitments will continue. We have had to put a hold on our new research grant round due to lack of funding. It is unlikely that we will fund any new research in 2020. **UK**

The lab where our funded pancreatic cancer research occurs was transitioned to COVID testing research. We hope that is a temporary change. **USA**

Covid-19 has had a catastrophic impact on clinical trials, with many existing trials paused and no new trials approved. Where there are already too few treatment choices for women with ovarian cancer, the cessation of trials will have a highly detrimental impact. I fear that it may take years for the research and new treatments pipeline to recover. **UK**

Advocacy Activities

In terms of influencing or lobbying activities, three-quarters of the respondents to the survey said they undertook such activity (75%). Almost two-thirds of these organisations (64%) have had to delay activity, and one-third (35%) have altered their messaging. For some it is about trying to ensure that treatments for patients are not delayed.

Struggling with health providers not to postpone the therapy of lymphoma patients. **Bulgaria**

For others meetings and conferences have moved online, and some have taken advantage of the new digital platforms.

This year, we pivoted our in-person event on Capitol Hill to a virtual campaign. We are hosting our first virtual Advocacy Week to give our community the opportunity to come together and participate in meaningful and impactful actions throughout the week to ensure our priorities are heard on Capitol Hill. Additionally, we are now conducting all of our meetings with Capitol Hill staff via conference call or video platform. **USA**

Of those who undertake advocacy activity, four in ten (40%) expect to have to adapt their future activity as a result of the pandemic.

It is difficult to focus people attention on pancreatic cancer, since the pandemic is now a world health emergency. **Italy**

Things are going to take a lot longer as the Health Minister has other priorities. **Australia**

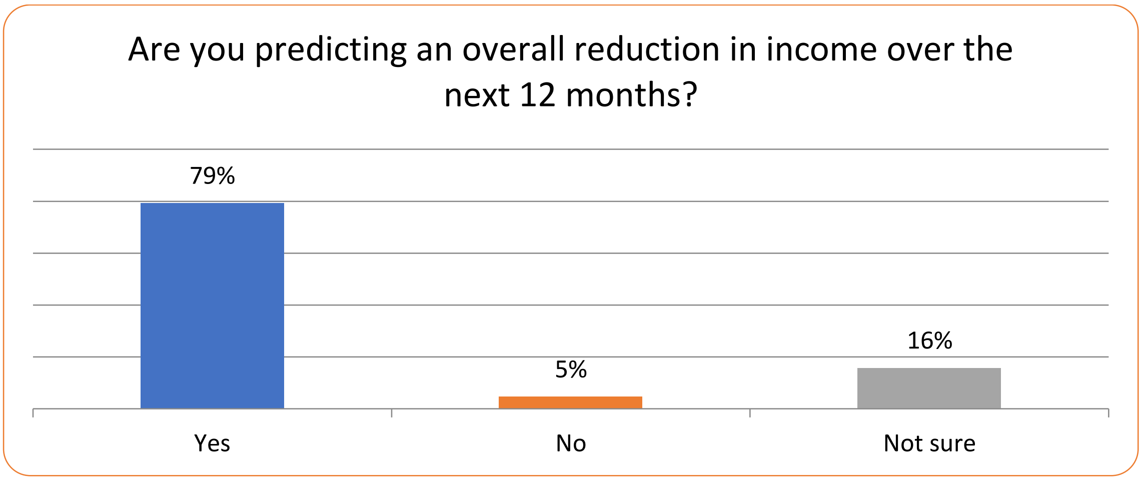
To make advocacy for don't have late diagnoses after pandemic. **Brazil**

The Alliance's main objective now has been to advocate for access to treatment services for cancer patients as the lockdown rules prevented many rural patients to get to treatment centres (no transport).
South Africa

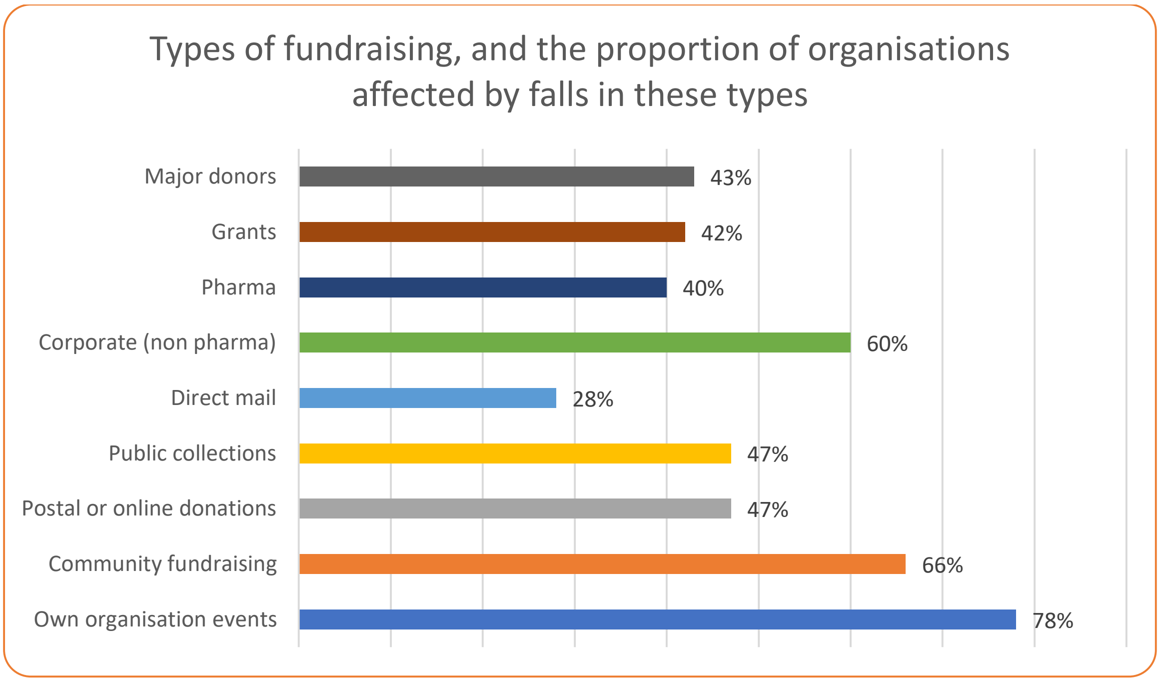
We are collaborating a lot more with other organisations, charities and the National Health Service so the relationships that support advocacy are better although we lose something by not being able to meet face to face. **UK**

Fundraising Activity

Almost nine in ten organisations fundraise to support their activities. A shocking 79% of organisations say they predict a fall in income over the next 12 months, with a further 16% not sure, leaving only 5% confident of their financial stability.



Every aspect of fundraising has been affected by the pandemic and this poses a really significant threat to the organisations and the work they undertake. The following graph shows the proportion of organisations that say a particular type of fundraising has already been affected:



The average (mean) expected drop in income was 46%, with responses ranging from 7% to 95%. The most common answer (mode) was 50%.

One in five organisations say that drops in income are currently affecting their viability (21%) and 45% say it may do in the future. Just 13% said it was unlikely to affect their viability either now or in the future. One organisation expressed a fear that some charities will not survive, and will result in mergers. A small number of organisations said they had seen an increase in funds from major donors, grant providers, pharmaceutical companies and monthly giving. However, between six and seven in every ten organisations are concerned for fundraising and philanthropy once the pandemic is over (65%).

Sixty percent of organisations are trying to find new ways to raise funds, and the range of ideas is very wide, from virtual happy hour webinars for 100 people (raised $12,000 USD), online celebrity auction, online gift shop, emergency appeal with free advertising in national press, to a virtual concert by leading performers. Sadly, one organisation noted an increase in donations 'in memory' of patients who have died during the COVID-19 pandemic. These are a few comments on new methods of fundraising:

At the moment we can survive and feel it is unethical to ask the public for money when many are facing dire financial personal circumstances. **Japan**

Online/virtual fundraising activities are starting to work well although they are not driving anywhere near the amount of money as traditional events have, however we are hopeful that they are keeping people engaged and giving us a platform to build on for the future. **UK**

We changed our 5K to virtual. Our participation increased by 80% and there were participants from 14 states. We were shocked and thrilled. **USA**

Adding a comedy event to help raise awareness and support our community and their mental health - increasing marketing. **Canada**

Pharmaceutical companies have been very generous in supporting efforts related to COVID education, and flexible in allowing previously awarded program funds to be redirected as needed. **USA**

Respondents were asked for any final comments in relation to fundraising. The following are a small sample that highlight the current challenges which will impact for some considerable time. A number of organisations would appreciate mentoring and partnerships, and there is a need to plan for hard times.

Again, we are open to and eager to partner with other organizations to use the importance of educating healthcare professionals and the community about ovarian cancer to raise funds that will allow us to continue these efforts. **USA**

We would like to be mentored in fundraising for our organization. **Kenya**

There is enormous uncertainty that will impact on our ability to build up our post-Covid fundraising. Uncertainty about the virus and a potential second wave, uncertainty about ongoing social distancing measures, and uncertainty about the depth of the predicted recession. We are planning for a worst-case scenario, and within that prioritising the delivery of digital support and advocacy services to ensure that we can continue to protect (people) and progress our mission. **UK**

Because we have passionate donors and volunteers, we're hopeful their commitment to our organization is steadfast in this economic climate. We cannot emphasize enough how important it is in times like this to have a sustainable base that is driven by committed supporters. We also have a strong calendar of fundraising campaigns, e.g. November Awareness, Year End Appeals, Giving Tuesday, etc. Giving Tuesday Now, this past May, did amazingly well for us raising over $40K. **USA**

It would be great to share successful examples from other organizations globally and join efforts to approach the pharmaceutical industry. **Uruguay**

Hoping international organisations can help us….now we have just personal helpers. **Morocco**

Fundraising has been extremely difficult due to Covid-19 with distancing laws and no group gatherings as well as the economic downturn. Crisis appeals have been unsuccessful and all outdoor events and major events have been cancelled. In Australia we have had to contend with also the fires earlier in the year where a lot of money was donated to leaving other foundations struggling to get donor support. **Australia**

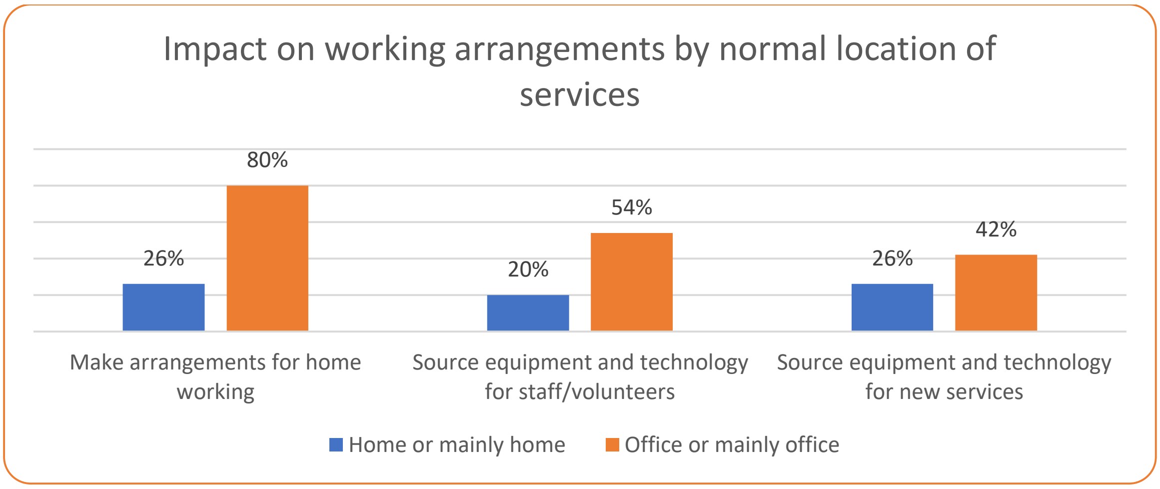
There are many patients, families, and supporters who have a difficult life because they have lost their jobs or have lost income, so I think that it is necessary to engage in patient group activities that do not cost much money. I am wondering what to do about the cost of traveling to IGCS in Italy this year. **Japan**

We may find that emergency funding helps mitigate losses in the current year but that it is next year that bears the full impact. However, it is difficult to know what will happen as the likely profile of losses and of recovery is what will make the difference to our income and services. **UK**

We are trying to learn more about the best approach to fundraising even in the face of reduced individual giving due to the pandemic; if pharma funding is reduced, we will have a bigger challenge ahead for our overall ability to manage with current staff and programs. **USA**

Cost Control and Physical Working Arrangements for Staff and Volunteers

Seven in ten organisations have had to review their budgets and available income (71%), and 55% of organisations have already had to cut costs where possible. This is at a time when just over a third of organisations have had to source equipment and technology to enable staff or volunteers to work from home (36%), and to source equipment and technology to deliver new services (37%). Those organisations who were totally or mainly based in offices were more likely to have to undertake these activities as the graph below shows. Just under a third of organisations have had to review protocols to ensure data and patient protection (31%).



The following quotes highlight the types of issues organisations have had to face, and it is clear that these will be ongoing. If cuts haven't already been implemented it seems likely they will, and they will impact on services for patients.

Webinar registration licences had to be purchased to expand numbers participating as well as additional user licenses for other programmes to enable work from home arrangements; our patient resource manuals are being sent directly to patients across the country (additional shipping costs) instead of just via hospitals and cancer centres given most resource centres in hospitals are closed during COVID. **Canada**

All vacant positions put on hold. 25% of staff furloughed. Rent reduction negotiations. Salaries frozen. Cancellation of all face-to-face events. **UK**

When the pandemic hit, within the space of two weeks, we moved our Patient Central call center from a wholly in-house patient support operation to be remote. This move was completely seamless to patients, and there was no interruption in service. We equipped 17 case managers with computers, introduced a new phone services allowing us to triage and transfer patient calls to remote staff, and deployed an encrypted, secure server to ensure that confidential patient information remains just as secure as if the patient's call was being taken in the office. **USA**

We had to borrow and buy a laptop, we reduced the budget, we may have to lay off one employee in the future. **Croatia**

All employees will continue working from home for some time to save resources. Furthermore, our staff is donating a percentage of their salaries to continue our mission of patient support. **Mexico**

We had to make 100k plus worth of savings by looking at direct costs straight away - some of these are related to now cancelled events but others are related to pushing back some activity to year end or even later such as the printing of new booklets. These initial savings were just one element of a wider range of measures to support finances in the short and medium term. **UK**

We have gone through a process of reaching out to all our service providers to see if we could put a hold on services not being used in the office. We have also asked our Landlord for rent relief. **Australia**

In terms of working arrangements for staff and volunteers, again there have been a number of changes, with more likely in the future as well. 11% percent of organisations have had to make some members of staff redundant (lay-offs), and 12% have been able to furlough some staff (a government scheme supporting wages of staff not able to work). Almost a quarter of organisations have had to alter staff roles (23%), and over half have had to do the same with volunteers (56%). Additionally, 10% of organisations have seen higher levels of staff or volunteer sickness.

We have accessed the Job Retention Scheme (furloughing) available in the UK and furloughed up to 40% of staff. We have paused all volunteering that is face to face. **UK**

The government's employer assistance program (minimum compensation for workers who cannot work) does not apply to NGOs. We no longer have engaged volunteers. **Croatia**

We spent 6 months with an HR firm attempting to recruit pro bono support for our operations. We were two weeks away from securing it, and then it fell through due to the disruption of Covid-19. **New Zealand**

All of our community outreach programmes are on hold until further notice. **Barbados**

Working home was very difficult to coordinate since we had not planned and costed for extra facilities. Due to technology challenges we have had to incur high airtime charges. **Uganda**

Due to the demands of working on new strategies, implementing new fundraising/events online, working from home and home schooling, our staff with children have struggled. One of our staff members has now been put on extended sick leave due to not coping. **Australia**

Impact of COVID-19 on Cancer Diagnosis, Treatments and Patients

Respondents to the survey show a major impact of COVID-19 on the diagnosis of cancer and various component parts. Situations can vary region by region within a country.

Two-thirds reported cancellation of screening programmes in their country (67%), almost six in ten say there has been a drop in urgent referrals for suspected cancer (59%) and 69% report a drop in the number of people seeking help for potential cancer symptoms. Almost half of respondents say there has been a reduction in access to pathology services to aid diagnosis (44%). A few respondents from countries such as Gibraltar, Israel, Japan, Russia, Slovenia and South Korea said there were no such impacts on services, and in Switzerland it was reported that ‘it is back to normal already’.

In our country there is county lockdown hence most of the counties are locked out of Nairobi. **Kenya**

Patients dropping out of treatment because of transport to access services in the only treatment center leading to increased death of Advanced Breast Cancer patients. **Uganda**

Care is being managed differently according to jurisdiction. Some have not changed, some are different. **Canada**

Results of pathology tests are taking longer to be returned. Generally a result would be returned within 48 hours. Since COVID-19 results are taking up to 7 days to be returned. **Australia**

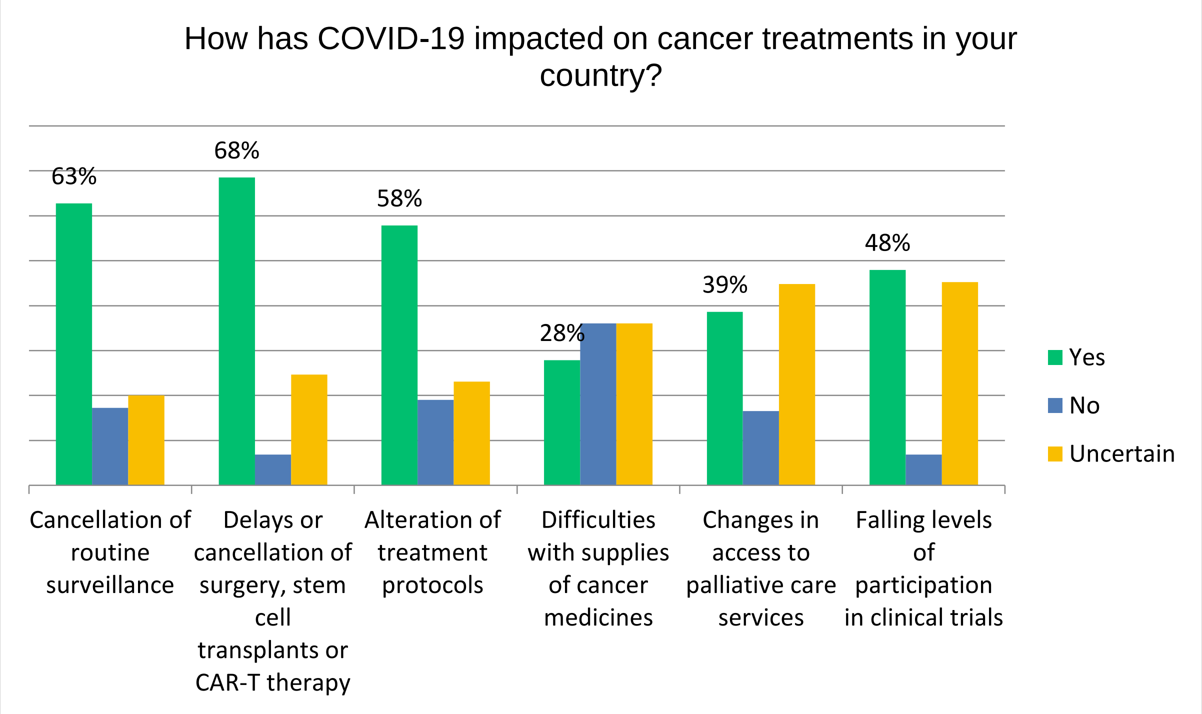
Our government is afraid of collateral damage: people with cancer symptoms who haven’t been to the hospital and who will be diagnosed in a later stage because of it. **Belgium**

There has been a very significant impact too on cancer treatments, but this varies not only by country, but region and even hospital too.

Surveillance has moved to phone consultation in most cases - delivering bad news has been more difficult. **UK**

Where applicable, oral treatment were sent home by some hospitals and there were initiatives by some Pharma companies to do this service on behalf of Hospitals. **Italy**

Every hospital, every patient, every city is different. These things should not be presumed to be happening across the board. For example, we have heard from the Health Care Professional community that patients believe that because one hospital is having a problem that all hospitals are having a problem. Many hospitals are open for business and begging for their cancer patients or high-risk patients to keep their appointments. **USA**



At the beginning there was a huge chaos. Generally everything was stopped. But day by day we moved forward and now after two months all is again on the track. There will be more patients and it will be busier time and for sure we will have more deaths because of cancer not COVID-19. But it is hard to say what is the scale. The problem now is that the patients are afraid of COVID-19 and they do not come to hospital. **Poland**

In terms of the impact on cancer patients, it is clear that respondents are very concerned about the reported increase in stress and anxiety, and isolation (88%, 92%). Some patients are having difficulty accessing food and medicines (48%) and 60% of respondents say the pandemic has increased financial hardship.

Majority of patient are becoming depressed since relative avoid them to interact with the community and patient members in fear of COVID-19 infection. **Kenya**

Unemployment levels in the states similar to depression era. This has been a real challenge as many have lost insurance as well as jobs. **USA**

Many of these areas are not as pronounced in some states where restrictions have been lifted. But, even in those states, there is anxiety and hesitation to be back out in public, by many citizens. And although most foods and supplies are adequate, it is still difficult to find viable cleaning products, paper products and hand sanitizer. **USA**

Thankfully there is only a minority of respondents who report that cancer care is being carried out in hospitals treating COVID-19 patients with no special arrangements in place (9%) though there is some uncertainty. The largest group of respondents report that cancer care is being undertaken in hospitals treating COVID-19 patients, but with special arrangements such as COVID free entrances. Just 15% reported that patients were being treated in COVID free hospitals.

Nearly a half of all respondents report an increase in remote consultations (42%), with a similar proportion reporting it ‘to some extent’. In Brazil a new law is being passed governing the use of telemedicine but it is ‘not yet routine’.

National or Local Guidelines Relating to Cancer Care During the Pandemic

Seven in ten organisations said they were aware of national or local guidelines relating to cancer care during COVID-19 in their country, and just under half (47%) said they were clear. A further 36% said they were clear to some extent. However, in some cases they were slow to be developed, and they can differ quite widely between countries.

The protocols and guidelines are consistent throughout all hospitals Australia wide. Ensuring a consistent message across Australia has been sent. **Australia**

The GOC [Government of Canada] has indicated best practices - whether that is being picked up everywhere is uncertain at this point. **Canada**

Between counties there are large differences. If you follow international Facebook patient communities this can be stressful. **Netherlands**

By now, not in the beginning. **Germany**

Guidelines are provincial based and continually evolving. Guidelines are complex for patients to understand. **Canada**

The guidelines vary from state to state and, even within one state, from community to community. **USA**

This is a new and challenging environment for clinicians/ haematology consultants so in drafting recommendations or guidelines they are having to move quickly to be responsive and with little or vague evidence available e.g. who should be shielding and who should not - getting consensus on guidelines can take time. **UK**

A third of respondents left final comments about cancer care in their country. Some were relieved that the impact has not been greater, and praised the response of their nation and government, or local area.

All was very well organized, so the death toll was very low and number of struck by COVID-19 as well. **Slovenia**

The government is working to very hard to protect all persons living in Barbados and especially those with chronic disease. **Barbados**

In Texas and specifically in Houston, where there is a world-renowned cancer center, with restrictions lifted, things are pretty good for those with cancer. **USA**

Australia had the advantage of learning from our European family which helped to shape our response - to date we have done very well. **Australia**

All patients we are working on peer support during COVID 19 pandemic get help, medical treatment even with experimental drugs for AML with great results only problem is the same with or without the pandemic how to survive cancer? **Croatia**

Even in countries where respondents felt the situation had been managed well, there was also concern about the less obvious impact of the pandemic on cancer patients.

I feel relieved that the impact of COVID-19 on cancer care is not so big in Japan so far. But more cancer patients will go through sociological problems than before such as anxiety derived from financial problems caused by COVID-19. **Japan**

Psychological elements to vulnerable groups badly managed, not managed at all, e.g. fear cancer patients face is not discussed. It has great impact though, people do not go to clinics because of that. **Finland**

Some respondents (South America) commented that they were still to reach the peak of COVID-19 infections and so were early in the cycle. However, the majority of comments portrayed deep levels of concern for current and future patients, and/or health systems and policies. This was true in a very wide variety of settings, and several warned of a catastrophic impact.

We are struggling to get a coordinated and funded intervention for cancer specific needs in covid times **South Africa**

For the past two years, we have finally prepared a national cancer control plan that was not adopted by the government because the focus was on the epidemic. **Croatia**

It is estimated that the delays in diagnosis and treatment will greatly impact on survival and outcome. This will be particularly true for pancreatic cancer where speed of diagnosis and treatment is absolutely paramount. **UK**

As a result of covid-19 the diagnostic and treatment of cancer patients was postponed and delayed, sometimes fatally. **Bulgaria**

Patients faced major challenges including missed appointments, treatment and emotional support due to total lockdown of services including public and private transport. we lost many patients who had difficulties accessing palliative services. **Uganda**

Covid-19 has had a catastrophic impact on the care of women with ovarian cancer in some part of the UK. Surgery postponed and significant non-evidenced based changes to the treatment pathway e.g. no chemotherapy for women with platinum resistant disease, lack of access to counselling services and palliative care. There is a significant backlog in the system now and the concern is that those women whose surgery has been postponed may be overlooked as others with less advanced disease may be prioritised. I fear that the combination of the sharp reduction in referrals along with delays and cancellation of life-saving treatments is a highly dangerous perfect storm that will lead to the needless loss of thousands of lives of women with ovarian cancer. **UK**

The present situation in Mexico is confusing: Government recommendations differ from WHO recommendations. The Mexican health system was going through changes just as the pandemic arrived, and the country was unprepared to confront this pandemic. **Mexico**

My country is undergoing a sustained crisis in all areas; Before the pandemic, oncology patients faced serious problems due to the lack of access to medications, supplies, diagnostic and control studies, failures in hospital services, and the flight of doctors. With the pandemic, even when not many positive cases are registered, the problems for the patients increase. **Venezuela**

One organisation chose to highlight the severe impact of the pandemic on its own ability to connect in large numbers with patients and on the impact on staff members of working in these difficult and uncertain times.

As a small organization, it's challenging to get a handle on the actual impact on our patient community. we don't have the resources that other larger organizations have to do surveys and analysis - we are doing all we can to keep our programs and services functioning and being available for individual patients that require our support along with doing our best to keep funding coming in so we can actually pay the small number of staff we have and try not to burn everyone out by forcing them to work way harder than ever to keep our organization functioning. I'm very concerned about staff burnout going forward. **USA**

There was also a reminder that COVID-19 is not necessarily the only new challenge organisations have to face.

During March precisely at March 22 2020 early in the morning our capital Zagreb was hit by 5,6 earthquake since than we have had at least one earthquake a day until today. So COVID 19 is not our only concern. **Croatia**

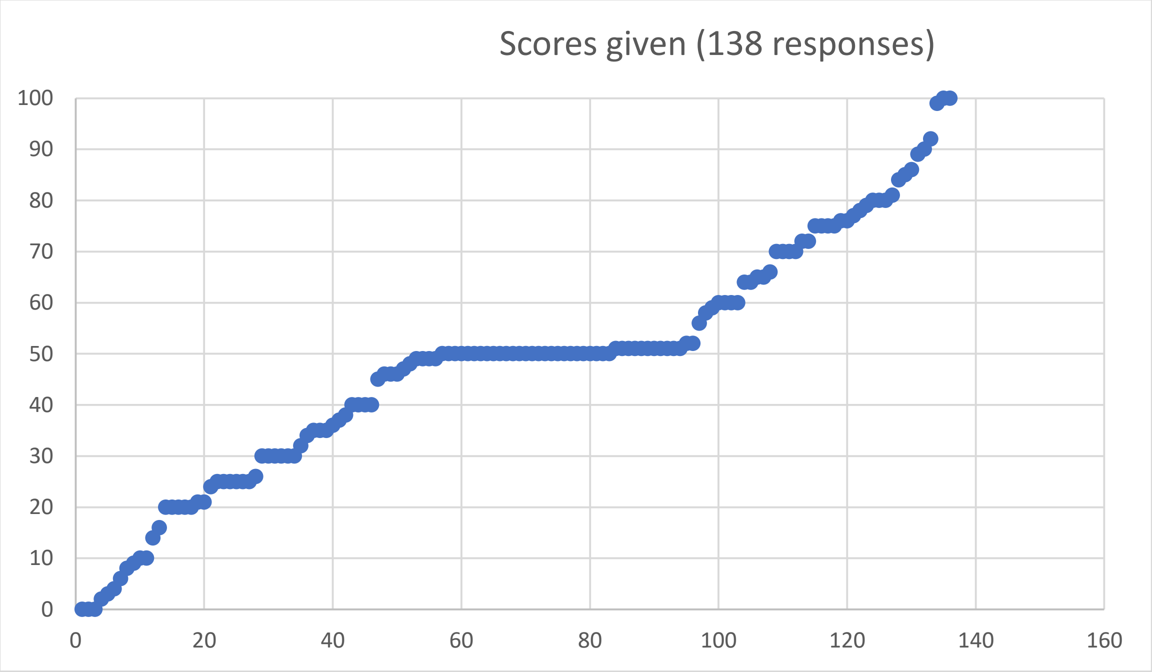
And finally, one organisation expressed a desire that organisations should not deter from collecting data about patients and their experiences, and that where possible this should be done in a coordinated or at least similar way. Also, that we should not lose the innovations and improvements that have been made during this time.

1. Post COVID-19 (if there is such a time) we will need to carefully look at any data that is collected to show the specific impact of COVID on lymphoma patients - I'm not sure about the extent to which data is being collected for specific cancers and lymphoma but in an ideal world all countries would be collating lots of this information in similar formats so that we can make sense of what the totality of what the data tells us. I fear that this is an area where we are not doing as much as we should be and that this is something that will be important for cancer care in future. 2. Patients have queries around vaccines - will they work for them, what is the impact of treatment on their immunity pre and post vaccine - this is something that will be of increasing interest. 3. COVID-19 is also driving innovation and improvements not just in our charity services (e.g. the move to digital) but also in terms of how the NHS is set up to diagnose, treat and care for cancer patients - things are being accelerated (cancer hubs, virtual consultations etc) that were previously being discussed but possibly some time off so it is important to see how we can build on this innovation going forward (including e.g. the NHS volunteering scheme which has mobilised lots of people to support others). **UK**

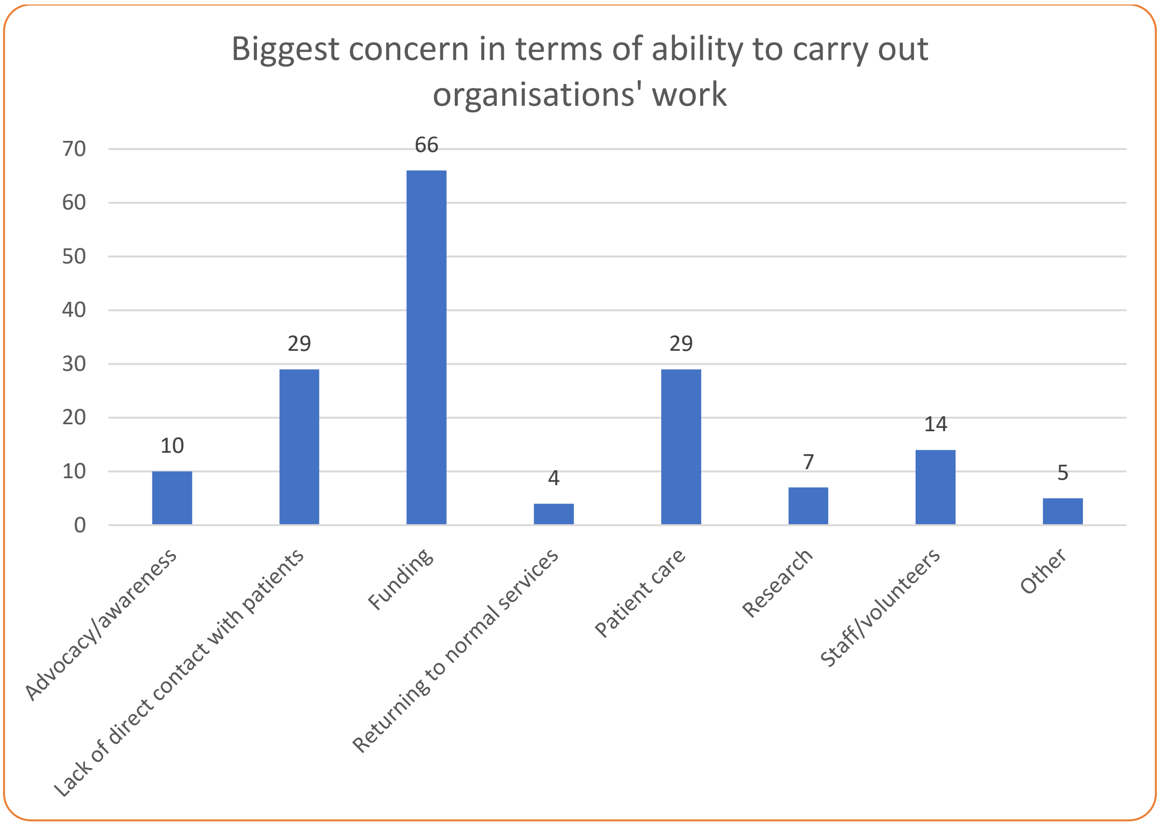
Level of Challenge Faced, and Advice to Others

The closing questions focused on the extent to which COVID-19 had challenged organisations' ability to carry out their work, and advice they would offer to others going through this.

Organisations were asked to score (0 to 100) with zero meaning no challenge, and 100 the greatest imaginable challenge. The average score was 48 with a fairly even distribution of results.



Organisations were then asked to say what their biggest concern was in relation to their work and the pandemic. Answers were then tagged into 8 categories. As you can see from the graph below, issues relating to funding were most prominent, followed by concerns relating to patient care and lack of direct access with patients.



In terms of advice for others, organisations were very generous with their comments. Broadly speaking they fell into three categories. First was the urgent need to embrace new technologies and ways of reaching patients and others who benefit from the organisation's services. The message was also that it was OK to start small and learn the lessons, but do it as soon as possible. Second was the need to review your plans boldly and last but not least the importance of collaborating, sharing data and ideas. That also included being engaged and active with your coalitions.

Don't give up. Hopefully COVID will pass, but even it is remains amongst us for some years, we must continue our invaluable work. **Australia**

Be flexible and open to doing things different than in the past. Being nimble enough to make changes quickly is important to maintaining a relationship with patients and caregivers. **USA**

Raise voice since the beginning. **Italy**

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 shine for them. **Barbados**

It's important to be flexible and be able to pivot. We've been able to switch everything to virtual very quickly. The depth and diversity of our communications with all constituent groups has also been really important – staff, volunteers, patients, donors, HCPs, etc. We've been vigilant in staying connected to all stakeholders. **USA**

Embrace digital communications wherever possible- at however basic a level - to establish a means for women to connect with each other, and offer them the opportunity to ask questions of clinical experts. It need not be technically sophisticated, but it will make an enormous difference. **UK**

It’s important to hold online seminars for patients with some lectures of specialists focusing on the latest information on cancer care related to COVID-19. **Japan**

Extend your digital support and arrange videoconferences, online support while seeing a face is crucial. **Portugal**

We have successfully run a patient support group online - we had eight participants and all our patients involved loved the fact they could connect and see other patients and chat. Since the trial was very successful we are looking to run more patient support days in the coming weeks. **Australia**

We need to analyse the impact at country level and develop new strategies without affecting the quality of work we do. **Uganda**

Have clear management plans. **Australia**

Working more closely together, sharing learnings and working out how we can do things differently - can mean that we might end up with some great new learnings through all of this. **UK**

We do see opportunity in learning from each other, as this is a situation that affects everyone globally, and different countries are taking different approaches, so we believe there is a chance to learn about best practices as a community of global advocates. **USA**

With the short-term impact on income there is a need and a tendency to focus on bringing in money now but there is a value to using the current situation to build long term relationships and improve partnership working; it is daunting to try and do things differently and in new ways and the pandemic has made us make decisions quickly and try new things (successfully) without the level of debate that we had previously - we have learnt that there is value in sometimes just taking a leap of faith and trying something - it is inevitably always easier the second time round. **UK**

Finding support for yourself as a leader and for your team - we all need to find time to take care of ourselves as well as the patient communities we serve; where possible lean into the larger umbrella organizations for help and support. **USA**

Collaboration will play a vital role in the recovery. I welcome that this survey is part of a concerted global effort to ensure that the voices and concerns of people with cancer are heard now and beyond the pandemic. Well done all. **UK**

COVID-19 is a global pandemic and cancer patients all around the world have similar worries, concerns and questions - we are a small/medium organisation working in one country but believe in the power of community and coalitions and so this survey is a very welcome part of looking at this from a greater perspective. **UK**

Please, everyone be safe. But, be rational and don't be ruled by fear, when there are facts and reality available to direct your actions. **USA**

Appendix

About the Survey

The survey was developed by 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 Coalition.

The coalitions involved distributed it directly to their members via unique links, and the survey was open from May 11th to May 25th. We would like to thank all of those who took the time to participate.

The data was cleaned to remove duplicate entries either from another individual in an organisation (in which case the most senior paid executive's response was used), or where there had been an interruption and one entry was a partial one.

In order to protect some potentially sensitive information, only the country of origin for quotes are given, and the full list of the participating organisations have not been included, as in some countries where there was only one response, it would be easy to identify a particular organisation.

All organisations who have quotes included have been contacted to ensure that any they do not want in the public domain are removed before the report is distributed more widely.

The programming of the survey (Survey Monkey), data analysis and report draft have been prepared by Frances Reid, Programme Director for the World Ovarian Cancer Coalition.

Each coalition will receive the raw data for the responses for their members but this will not be distributed any further.

12th June 2020

The Global Lung Cancer Coalition 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)

Irish Cancer Society (Ireland) has seen a 60% increase in requests through their helpline

Roy Castle Lung Cancer Foundation (UK) has seen a 25% increase in their helpline and a 30% increase via email and community referral

Formosa Cancer Foundation (Taiwan) has seen a 44% increase via phone/helpline; a 40% increase via their website contact us page; and 66% increase through their "e-care app"

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)

> *"Slower diagnosis, surgeries and also access to medication challenges with co-pays."* - **Lung Cancer Canada**

> *"I think that COVID patients have become a priority now and lung cancer patients have become less important, most of the Pulmonologists are with COVID patients not the lung cancer patients."* - **Respirando con Valor Mexico**

> *"At the beginning patients were afraid to come to treatment. Doctors also moved to phone call appointments and widening treatment time between treatments."* - **The Israeli Lung Cancer Foundation**

- 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 or email our secretariat at: glcc@roycastle.org