



COVID-19: Impact on Cancer Patient Organisations Worldwide in 2020



A joint initiative by



Coalitions participating in the survey



Additional material provided in the Appendix from IBTA



Undertaken in December 2020, this work updates and extends findings from a survey of cancer patient organisations worldwide, first carried out in June 2020.

ACKNOWLEDGEMENTS

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EXECUTIVE SUMMARY

This report highlights the findings of a survey of member organisations jointly undertaken by six global cancer coalitions in December 2020, all members of the Global Cancer Coalitions Network (GCCN), with additional commentary in the Appendix from the GCCN member International Brain Tumour Alliance, who had already conducted similar work.

The survey builds on work undertaken in June 2020 and provides important insight into the impact of COVID-19 on cancer patient advocacy groups around the world, and those they support.

The survey in June 2020 gave a distressing insight into the then-current and projected challenges for member organisations who provide a wide range of services including research funding, advocacy, awareness raising, health professional education and critical support and information services for patients. As the pandemic has shown to be persistent and aggressive, the GCCN wanted to ascertain whether the dire predictions of June 2020 had materialised, and how the vital organisations it supports were coping. In this second survey, 104 organisations from 46 countries participated.

Six months on little has improved. The majority of organisations are providing essential services for a patient population whose needs for support and information have increased significantly. Yet, they are doing so in the face of enormous financial and logistical challenges including reduced budgets, fewer staff and an unparalleled drought of volunteers. Organisations report a clear and present danger to this sector with few signs of a reprieve on the horizon. Funding prospects remain low while it is expected that patient need will only increase. Cancer services are already strained with the backlog of patients who have not been screened, investigated, or treated during the pandemic. Healthcare professionals are exhausted and many people living with cancer or experiencing cancer symptoms have become even more anxious about their well-being and access to safe health services.

The ongoing impact on current cancer research and future research funding threatens much needed progress, particularly for those with rarer forms of cancer or incurable disease.

The determination of the organisations represented here is incredibly high. Many have embraced some of the few positives of the pandemic in terms of rethinking services, models of engagement, and increasing reach with patients and their families and caregivers. Nonetheless, this comes at a price and there are already worrying signs of increasing staff burnout and an exit of some staff to more secure jobs not as affected by the pandemic.

There is, quite rightly, a desperate need to get cancer diagnoses, treatment, support, and research back on track, in spite of what is happening with the pandemic. The organisations represented by GCCN play a critical part in that process, in addition to the invaluable services they provide. Yet, they are in a perilous position and there has never been a moment where support for those working on the front line has been so needed. Without these organisations, vital services that often complement or replace healthcare services – some of which have been displaced by the pandemic – will disappear completely and the sector as a whole will be set back many years. Emergency funding must be made available to these organisations to avoid a devastating increase in cancer patients' unmet needs worldwide.


Key Findings

- **Two-thirds of the organisations that fundraised experienced a fall in income** in the 12 months to December 2020, with an average drop of 48%
- **All forms of fundraising were affected**, and almost all cases of a fall in income were attributed to the effect of the pandemic
- **Over one in ten organisations have closed temporarily**; some permanently
- **Only one in ten organisations believe their 2021 income will return to levels comparable to before the pandemic**
- **Almost half of the organisations say their ability to operate is under threat**, either currently or potentially in the future
- **Around half of the organisations say they do not have access to any national funding schemes** to help them to continue operating during the pandemic
- **Staffing numbers have decreased by nearly 20% on average** and volunteer numbers by 70%
- **For almost all organisations who remain open, there has been a radical transformation of services to incorporate virtual working, service provision and fundraising.** In many cases, this has increased the reach of organisations. Still, concerns remain about reaching those who are digitally deprived, such as the elderly
- **Demand for services has increased during waves of the pandemic**, with calls and emails mainly about the risk of patients catching COVID-19, how cancer treatment is affected, and difficulty coping with a cancer diagnosis at this time
- **Only one-third of the organisations that fund or undertake research have seen their projects unaffected by the pandemic**, with concerns for long-term progress and the research community
- **Fewer than two in ten organisations report cancer services such as screening and diagnostics as being back to normal**, with a slightly higher proportion of respondents saying services are worse than ever
- **Patient distress, isolation, and financial hardship have increased markedly in the last year**
- **Whilst half of the organisations that responded say lessons have been learnt at a national policy level concerning cancer care, one-third warn of fundamental mistakes being repeated in the future**



Our message is clear:

Cancer will not wait for COVID-19 to pass, if it ever will, and patient organisations are the key to minimising the devastating impact on people with cancer. Please do all you can to support them as a matter of urgency.



These findings and conclusions are supported by the members of the Global Cancer Coalitions Network:

- Advanced Breast Cancer Global Alliance
- Global Colon Cancer Association
- Global Lung Cancer Coalition
- International Brain Tumour Alliance
- International Kidney Cancer Coalition
- Lymphoma Coalition
- World Bladder Cancer Patient Coalition
- World Ovarian Cancer Coalition
- World Pancreatic Cancer Coalition

ABOUT THE ORGANISATIONS THAT PARTICIPATED

A total of 104 respondents from 46 countries have been included in this survey. They are members of the following six cancer coalitions:

- Advanced Breast Cancer Global Alliance
- Global Colon Cancer Association
- Lymphoma Coalition
- World Bladder Cancer Patient Coalition
- World Ovarian Cancer Coalition
- World Pancreatic Cancer Coalition

The greatest number of responses received were from the United States (21), followed by the United Kingdom (9), Australia (6) and Italy (6). All countries represented are listed on page 7. At the time of completion of the survey, most described their country as being in the second (57.8%) or third wave (12.8%) wave of the pandemic.

A third of respondents said cases were currently increasing in their country (31.2%) and just 8.3% said they were not currently in any wave.

Responses were cross-checked with the first survey of June 2020. Fifty-five organisations participated in both (52.9% of this sample, 35% of the original participants).

Most of the 104 organisations in this survey are cancer site-specific, with the breakdown as depicted in Chart 1. Together they are in direct contact with almost 600,000 cancer patients.

Half of the respondents said their staff and volunteers are currently working from home (50.5%), 16.5% are working mainly from home, and 18.4% said they were evenly split between home and office. In our previous survey 32% had been fully home-based prior to the pandemic.

Chart 1: Number of organisations (104) by cancer type

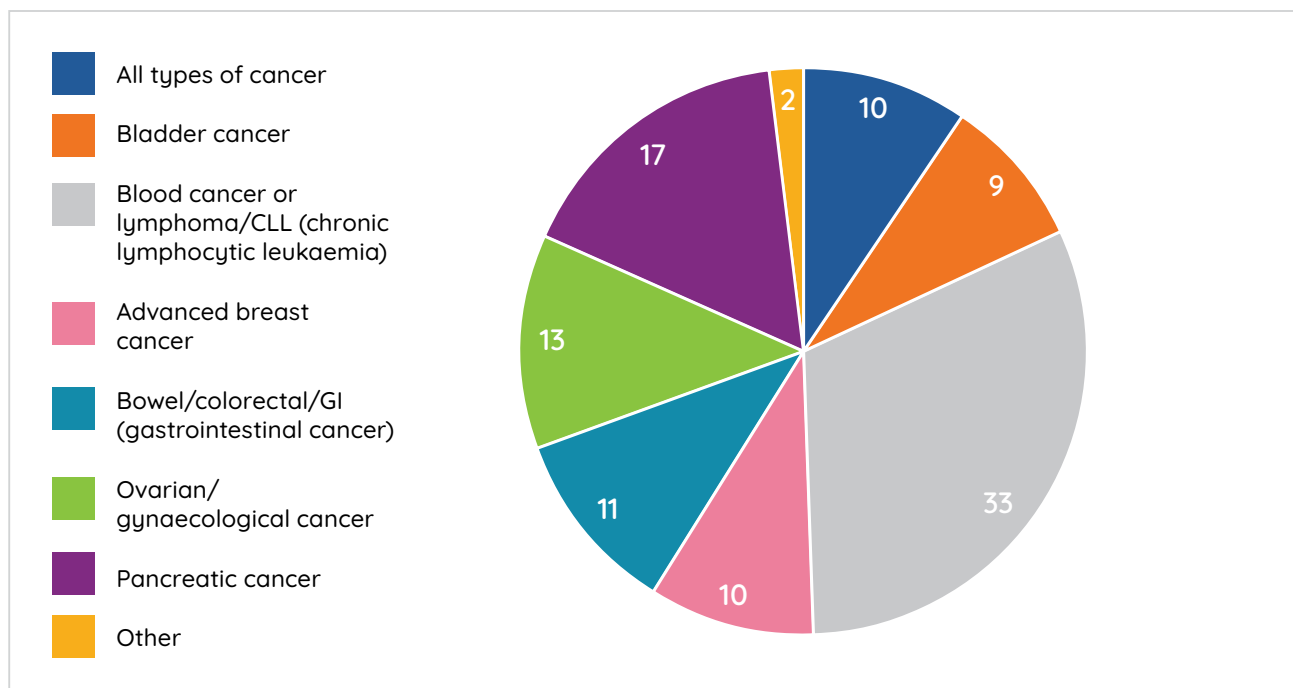


Chart 2: Responses by country (n=104)



Seven in ten organisations have paid staff (69.2%) and only 37 out of 104 organisations surveyed have more than five full-time equivalent employees (35.6%). For the seven in ten organisations who have staff, the average number of full-time equivalent posts in December 2019 was 21.2. This fell to 17.4 by December 2020, a loss of almost one in five posts.

Almost all organisations (95.2%) rely on volunteers to deliver their services. In total, just over 36,000 people were supporting these organisations in early 2020. For those relying on volunteers, the average number of volunteers per organisation fell from 369 to 107 in the twelve months to December 2020, a decrease of 70.1%.

Two organisations of those surveyed have had to close permanently due to the pandemic and 13 have had to pause services temporarily, primarily due to national or local restrictions relating to the pandemic. There may have been other organisations from the original survey who have also ceased to operate.

Fundraising Activity

Not dissimilar to our original survey, 83.7% of organisations (n=87) raise money to support their activities. In June 2020, 79% of these organisations were predicting a fall in income over the following twelve months, with an expected drop of around 46%. Only 5% predicted no drop.

For this survey, we asked whether income levels had fallen in the year to November 2020, from what was expected. Two-thirds (67.4%) of the organisations who raise funds had experienced a fall in income, with an average drop of 48%. The vast majority was directly attributed to the pandemic (81.7%) and another 15% of organisations citing COVID-19 to some extent.

Whilst the average fall in income was 48%, the range of falls experienced was very wide (10–100%). Concerning the organisations who experienced a drop of more than 50%, 21 organisations in eighteen high-, middle-, and low-income countries were affected. Bearing in mind that the sample sizes are quite small, it is, however, interesting to note that a greater proportion of ovarian and pancreatic cancer organisations seem to have been affected in this way, when compared to the others, and

that no charities dealing with all types of cancer experienced such dramatic drops (Chart 3).

In the year to December 2020, 22 organisations did not experience any fall in overall income (25.6%). They came from a wide range of countries, mainly during second or third waves of the pandemic. Those dealing with all types of cancer and possibly those dealing with blood cancers and lymphoma/CLL were less likely to have experienced a drop. However, most of these groups (16/22) experienced drops in income from some types of fundraising, but these were countered by increases in others, such as support from pharmaceutical companies, or online donations.

When asked whether organisations had been able to apply for emergency funding from their government, 80 replied, with 47 (58.8%) from 29 countries reporting no such scheme existed.

Fourteen organisations (17.5%) successfully applied for emergency government funding.

Chart 3: How different organisations fared, by cancer type (n=102)

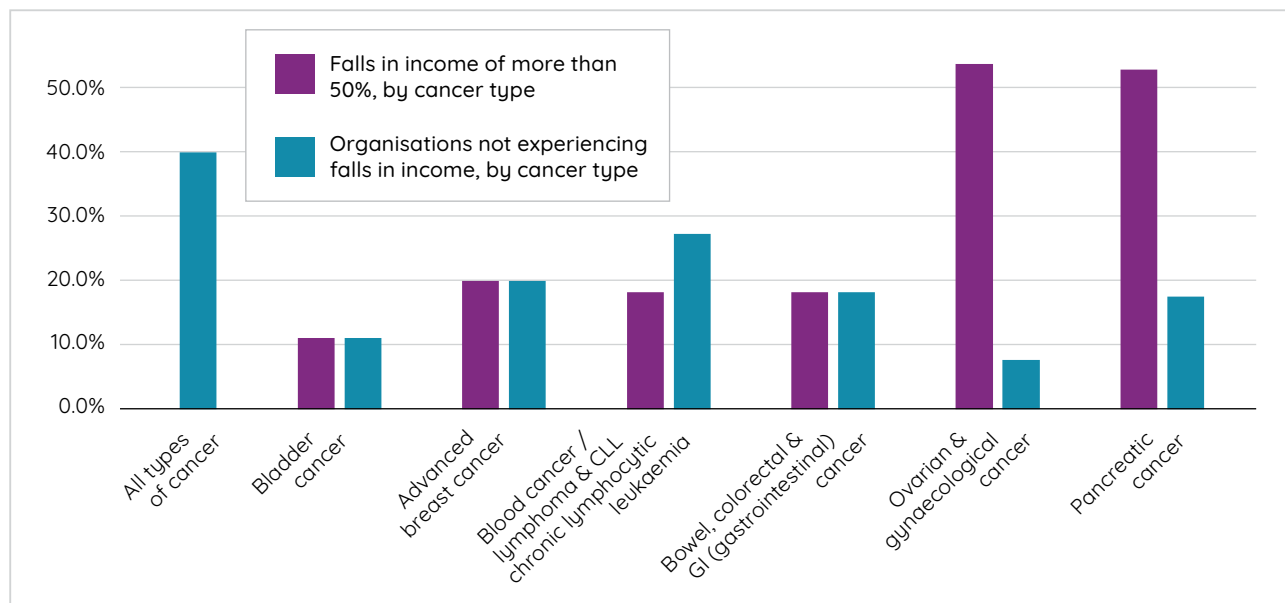
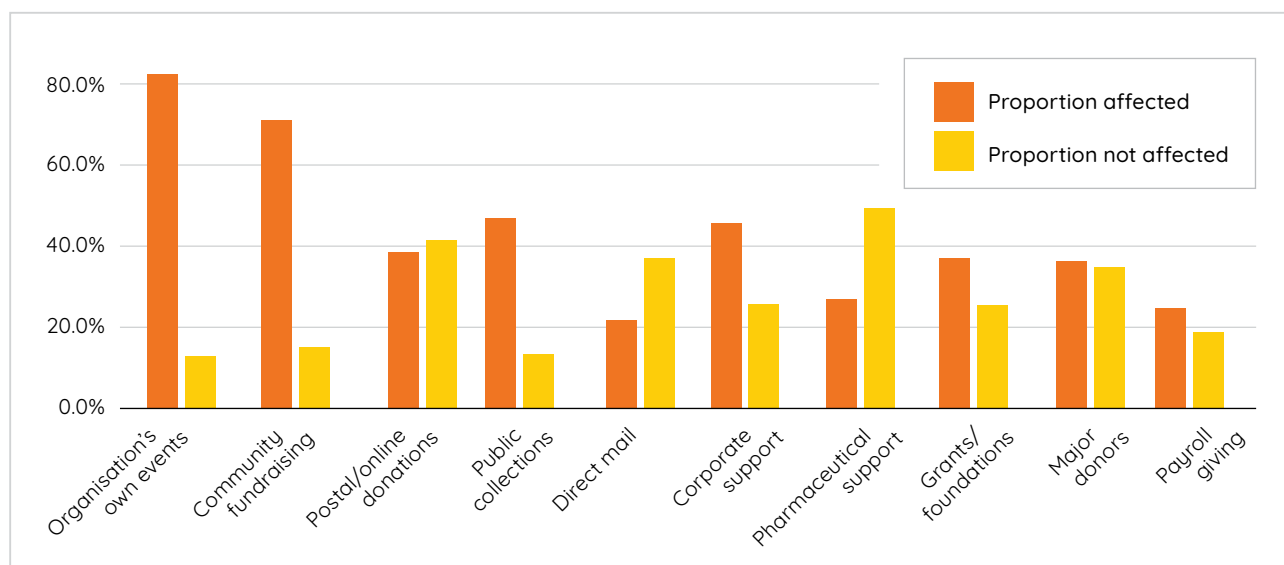


Chart 4: Categories of fundraising and how they were affected (n=80)



The organisations receiving emergency funding were all from high-income countries (Ireland, Canada, New Zealand, Australia, United Kingdom, Finland, and the United States). Of these 14 organisations, 12 still experienced an overall drop in income over the last year, with an average fall of 27.4%.

Current income levels are affecting the ability of one in ten organisations (10.8%) to exist, and a further 36.5% say this may be true in the future.

In terms of the types of fundraising, every single category was affected to varying degrees. Respondents reported that their own fundraising events were hit hardest (82.1%), followed by community fundraising (70.9%), public collections (47%), and corporate (non-pharma) support (45.7%). The categories least likely to have been negatively affected were pharmaceutical support (49.4%), postal and online donations (41.5%), and direct mail (37%).

Seven in ten organisations (70.9%) have tried new ways of fundraising, mainly online.

Looking ahead to 2021, just one in ten organisations believe their level of income will revert to pre-pandemic levels or higher (11.9%). A third of organisations say they think levels of income will remain around those seen in 2020

(36.9%) and 23.8% say they expect levels to increase from 2020, but not yet returning to pre-pandemic levels. Nearly one in six organisations (14.3%) expect to see further falls in income in 2021, with an average expected decrease of 35% compared with 2020 levels.

“We launched a new virtual event ... which was a week-long event. We added a new mobile donation software platform to support easier engagement along with a communications strategy to support our fundraisers. It was effective and we learned a lot from the experience that we will take into building upon this year’s event in 2021.”



“We have learned that asking and communicating with our patient community/fundraisers has helped us craft a better strategy for engagement. It’s always challenging. This year it’s been more intense and worrisome, especially given we had to eliminate the fundraising staff position due to an anticipated reduction in funding. This has left the fundraising work to be distributed among the remaining five staff members.”

Impact on Services

Our June 2020 survey demonstrated that many services had to be altered in the first wave of the pandemic. In this second survey, we were keen on assessing the longer-term impact of the pandemic on services. We also wanted to explore both the positive and negative aspects that such changes in services might bring, and whether there may be long-lasting changes as a result.

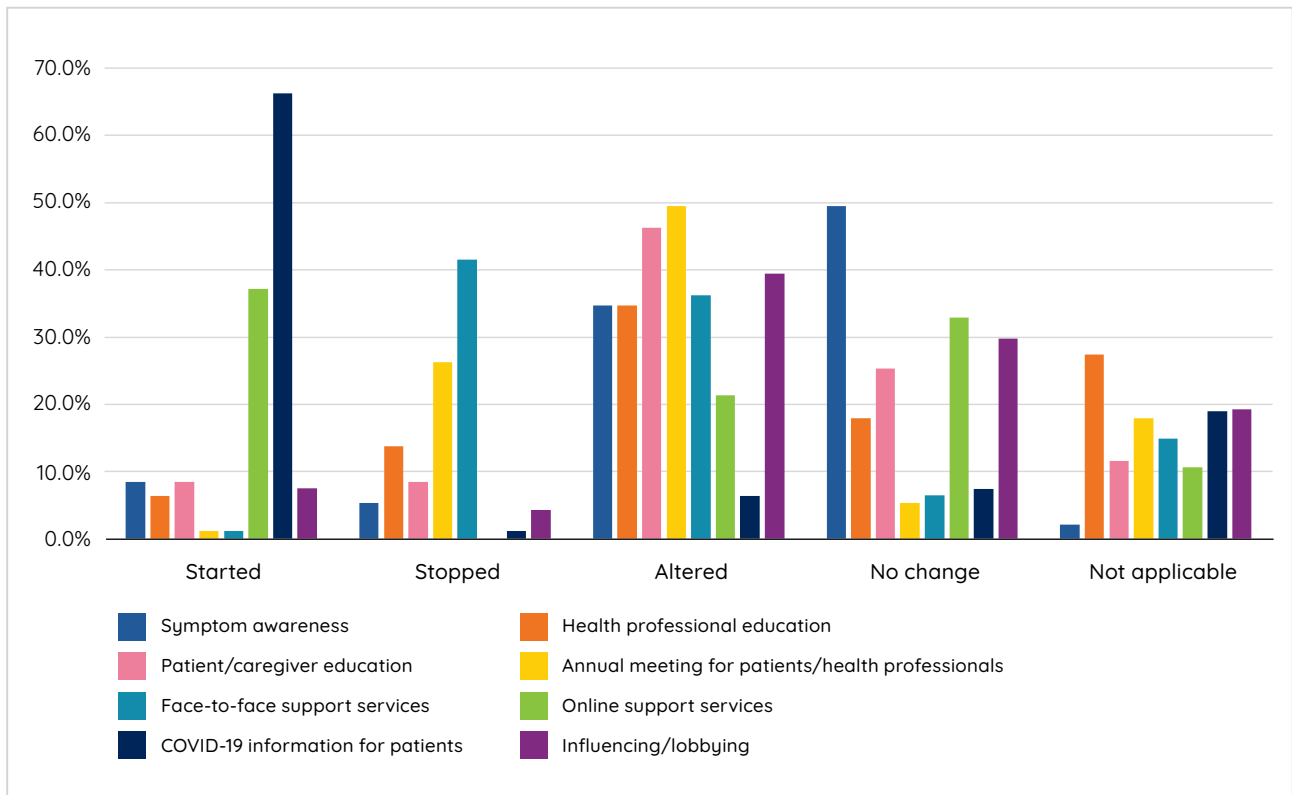
Different organisations carry out different activities, but, unsurprisingly, it was the face-to-face elements that were most likely to have stopped, such as face-to-face support (41.9% of responding organisations) and the organisation of large in-person annual meetings (26.3%). These categories also scored highly in terms of being altered (36.2%, 49.5%), together with patient/caregiver and healthcare professional education sessions (46.3%, 34.7%). The activities most likely to have been started were the

development of new information in relation to COVID-19 and online support services, with 66.3% and 37.2% of organisations offering these new services.

When asked whether their organisations had been able to use new technology and ways of working to the extent they would have liked, just over one in four organisations said yes, they had fully adapted to these changes (28.4%), and over half said yes, to some extent (56.8%).

By far the majority of respondents (80.0%) said that technology had helped to redefine how they connected with their community of patients and supporters in a lasting way.

Chart 5: The effect of the pandemic on service provision (n=95)



Some organisations (15.8%) had to spend extra money to be able to use new technology and 27.4% said they had to acquire new digital expertise.



“We are concerned about digital deprivation and the impact of this on patients who may previously have depended on non-digital services, for example, face-to-face events or hard copy information. We have made sure that our nurse-led support line, and wider support, was sufficiently resourced to help address this.”



“Our inability to travel has hampered our ability to meet with stakeholders... to understand the needs of the community in a face-to-face manner. Additionally, lobbying activities have halted and we are concerned that letters or virtual meetings are not going to have the same impact as testifying in person.”



“We have been able to reach a wider section of healthcare professionals with online educational events; we have attracted younger and different audiences to our digital peer support; we have trialled and put in place new services quicker than we thought we would be able to do; we have been able to save on costs which means that we have learnt to provide some services more efficiently.”

Nevertheless, over one in ten reported needing further help to make the best use of new ways of working (13.7%), and just under one in ten had significant problems with access to the internet and wireless networks (9.5%).

The benefits of using new technology outweighed negative aspects, but only to a minimal extent. Respondents were very positive about the ability to reach much wider audiences that had previously not engaged in online activities. This included some older populations, more rural, or patients that are less well.

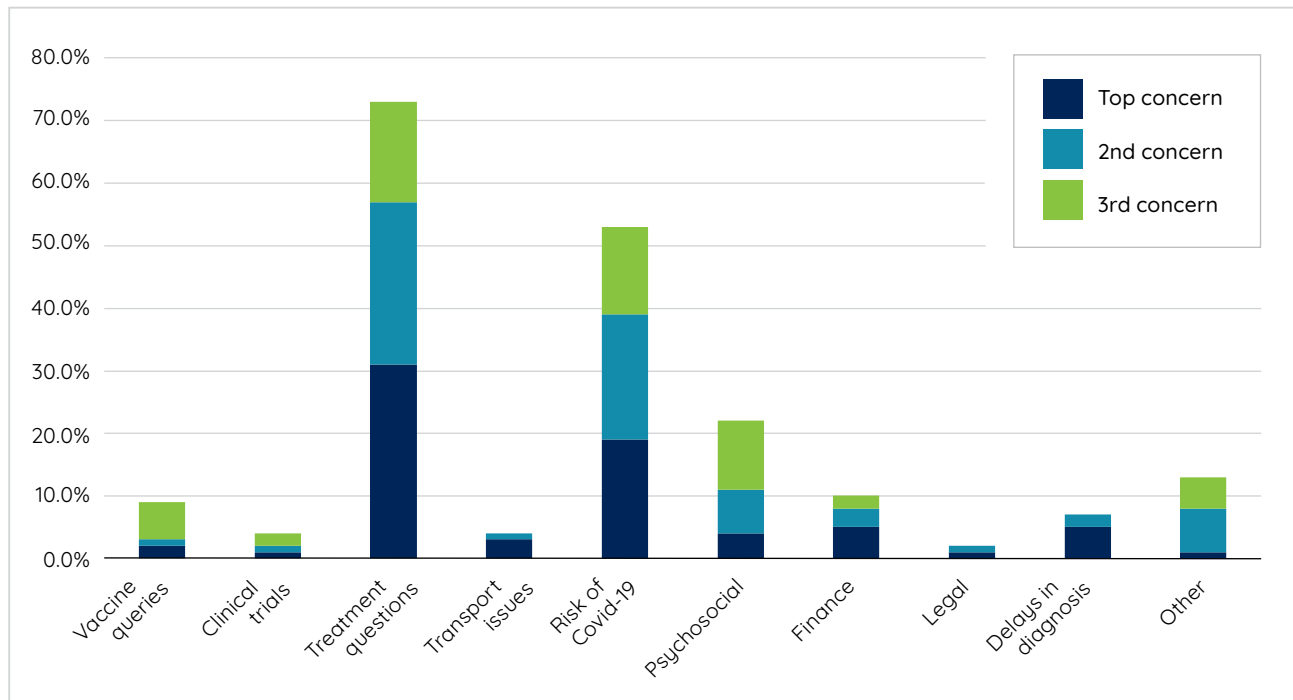
Less time was spent on travel, allowing more time for other activities. Having to suddenly rethink activities provided some organisations with the impetus to take a close look and re-evaluate all their services, bringing about greater efficiency, creativity and online presence. In total, some 49 out of 104 respondents made comments about the positive outcomes (47.1%).

However, the impact of necessary changes to service delivery and the lack of face-to-face contact was an issue for many organisations, both in terms of connecting with patients and supporters, as well as for staff and key stakeholders. Several organisations commented on the risk of staff burnout.

The greatest concern lay with the lack of face-to-face support for patients affected by cancer, and that some patients – in particular the elderly and others with limited digital access – were often excluded from the new services. In total, some 42 out of 104 respondents (40.4%) said there were important drawbacks to the changes in service delivery and working practices as a result of COVID-19.

It is clear that many organisations have had to change much of what they do against a backdrop of falling funds, reduced staffing, and volunteers. The strain on organisations is compounded when factoring in that for the eight in ten organisations who run helplines or online forums, over half (56.4%) saw an increase in calls and emails, with an average increase around 46%.

Chart 6: Most common queries raised (n=65)



Four in ten of the organisations who offer these kinds of services said that telephone calls and emails tend to fluctuate according to the local extent of the pandemic and associated restrictions.

For around three in ten, telephone calls peaked at the height of the first wave but have returned to normal levels; for another three in ten, telephone calls peaked in the first wave but have remained high.

This may be due to increased digital reach, according some of the responding organisations.

Organisations were asked about the three most common questions raised on telephone calls, emails, or online. As with the previous survey, the questions were dominated with issues around treatment, risk of contracting COVID-19, and psychosocial concerns.



“With the elimination in travel and intentional focus on asking our community what they needed, we have had the chance to do a deep dive into our current infrastructure and operations, looking at what works, what doesn’t, streamlining internal processes, technology and staff communications. This is something we always wanted to do, but we never took the time to do it effectively. Having done this work, we are in a better position to move into 2021 with streamlined operations and a plan for managing current and new initiatives.”



“Impact on staff stress and workload has increased exponentially with no chances of recovery time. We are very concerned about burnout and ability to keep up the current pace of work required to fulfil our mission and severely understaffed without much opportunity to afford additional resource support.”



Impact on Research

Half of all participating organisations said that they either funded or undertook research activities prior to COVID-19 (50.0%).

At the beginning of the pandemic, just over a third of these organisations' research programmes were not affected (36.5%), but four in ten organisations reported that their projects or projects they had funded had been paused, or had their scope reduced. Other projects had seen delays, research staff redeployed to the COVID-19 cause, or a mix of some projects paused or delayed, whilst others started.

In terms of the current impact, the situation has barely changed. Over one-third of projects or funding programmes is either reduced or paused (38%). One organisation spoke of placing the priority of existing projects over future ones, so whilst current projects are able to proceed, the availability of funds for future funding rounds has been reduced.

Another organisation described receiving external funding for a new programme to be

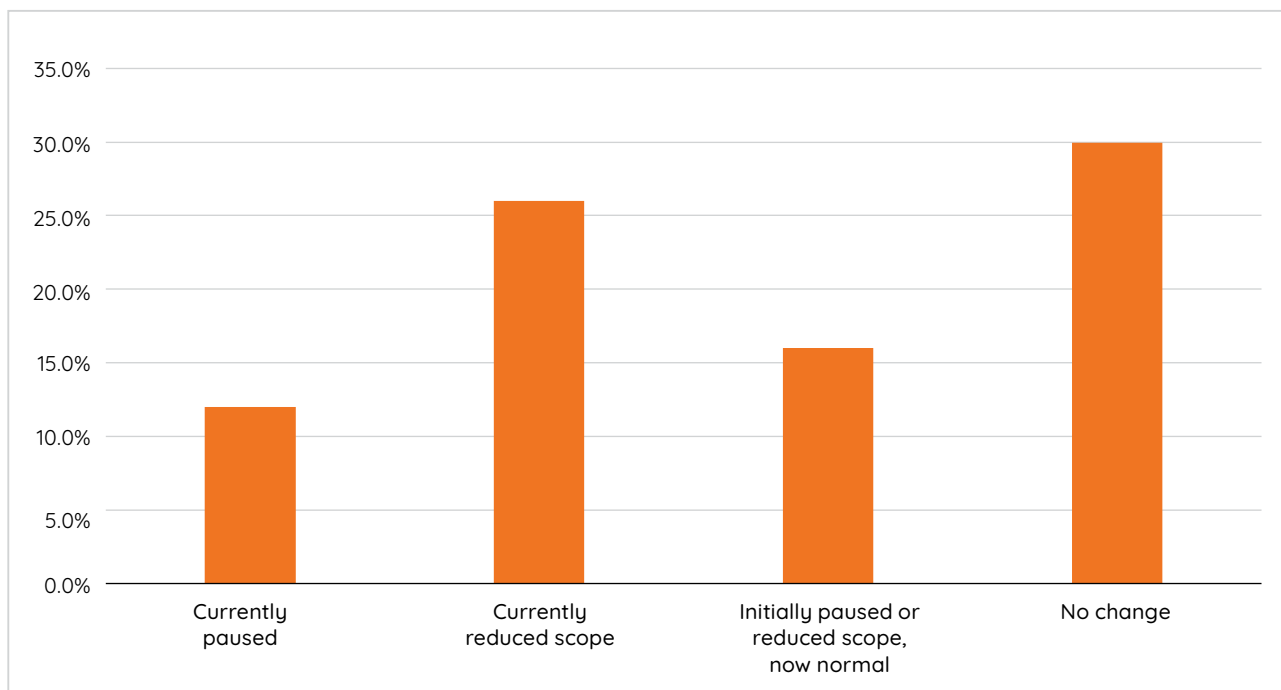
initiated, but had to withdraw existing funds for tissue banks, lab support and student grants that were drawn from their general research fund.

Half of the respondents were not overly concerned about the viability of current research programmes (51.9%), with the remainder either definitely concerned (23.1%) or not sure (25%).

When asked if they would be able to resume or continue research activities in 2021, just over half (52.9%) said yes, nearly one in five (19.6%) said yes, but at a reduced level, and nearly a quarter were still unsure (23.5%). Only one organisation said they would be unable to fund any of their planned research.

Concerns were raised by participants about the impact of reduced funding of research across the board, including by patient advocacy groups as well as government and health agency funding. Many focused on the negative impact of reduced research spending on the development of new diagnostic techniques, therapies, cures, and clinical trials.

Chart 7: Proportion of research projects or funding currently affected (n=50)



Some were concerned that advances that have already been made will fall behind and be delayed.

There is also worry about the loss of talent in the field, with early career researchers in particular having to find jobs elsewhere. Others highlight that, especially for rarer types of cancer, the situation is likely to become even worse, as so much is needed in terms of basic biological studies, and that funding will go to less risky projects, thus slowing down potential progress and widening the gap.



“

“We prioritised protecting our funding commitments to existing research projects so that they could be completed, and offer no cost extensions in order to achieve that. The most damaging impact of the pandemic has been that we were not able to offer a new grant in 2020. Funders’ preferences during the pandemic were to support frontline services to limit the immediate harm on [patients with] cancer. This was absolutely the correct focus. There is, however, huge collateral damage in terms of cancer research that will take years to repair.”



“Reductions in government funding for research were an issue before COVID-19. The reduction in cancer research taking place can only be a negative thing. All research output contributes to our better understanding of cancer ...improved treatments and quality of life. In the long term, decreasing cancer research will also decrease this potential benefit. We are also at risk of losing talented researchers who may be unable to keep or find positions due to a lack of funded roles and will therefore have to look outside of research for jobs. It will be difficult to entice this talent back into cancer research once they have left.”

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THE IMPACT OF THE PANDEMIC ON NATIONAL CANCER SERVICES & PATIENTS

Participants were asked a number of questions about national cancer services, such as screening programmes, diagnostic and treatment services, and the subsequent impact on patients. The results are a very sobering reflection that little is 'back to normal' and that in certain instances the situation is worse than ever.

As can be seen from the following charts, fewer than 20% of respondents in any category reported services that are essential to cancer diagnosis (screening, pathology and urgent referrals for investigation) to be back to pre-COVID-19 levels (range 6.9-18.2%).

In every category, except access to pathology, more respondents reported things to be worse than ever (range 12.5-20.7%), rather than back to normal. It is clear that the delays in cancer diagnosis will have a catastrophic effect on patients' survival chances.

Chart 8: To what extent are the following categories relating to diagnosis still an issue in your country (n=88)

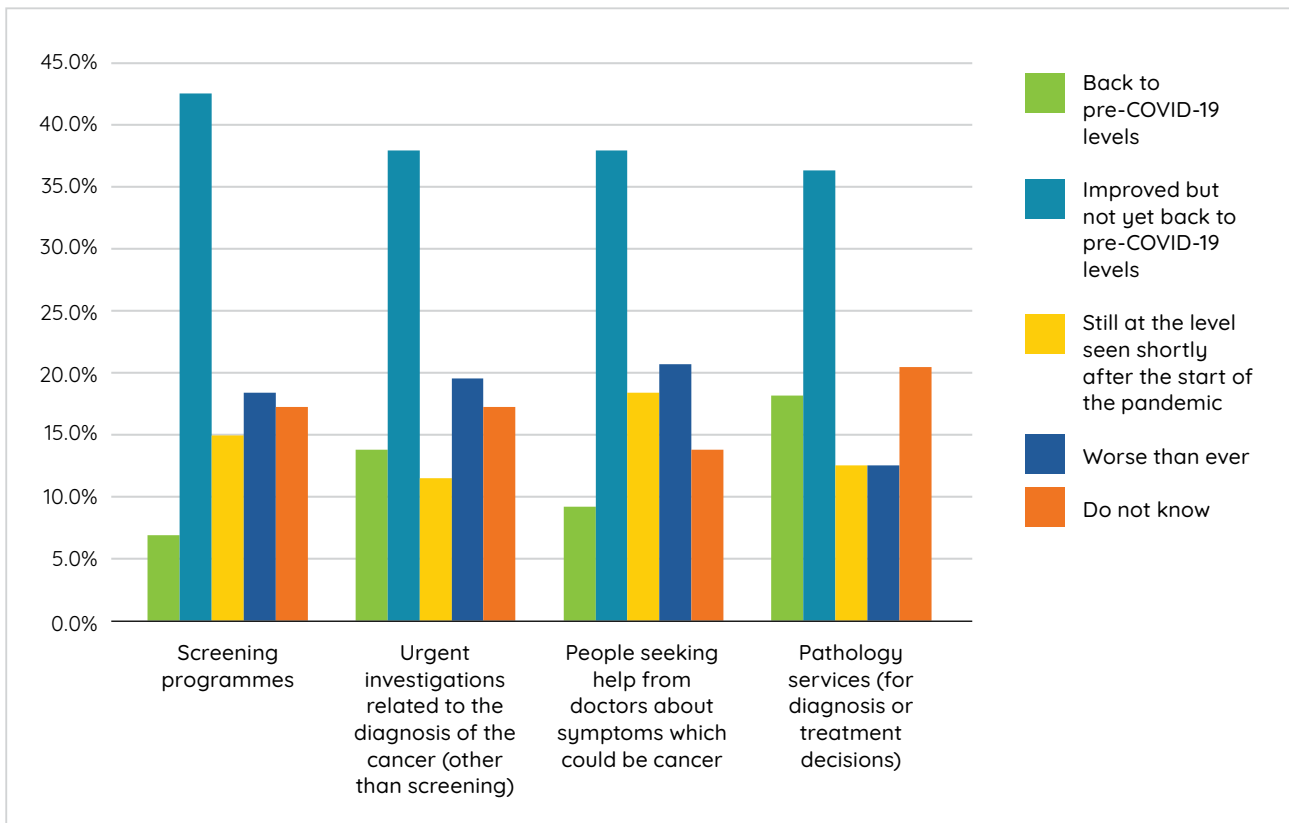
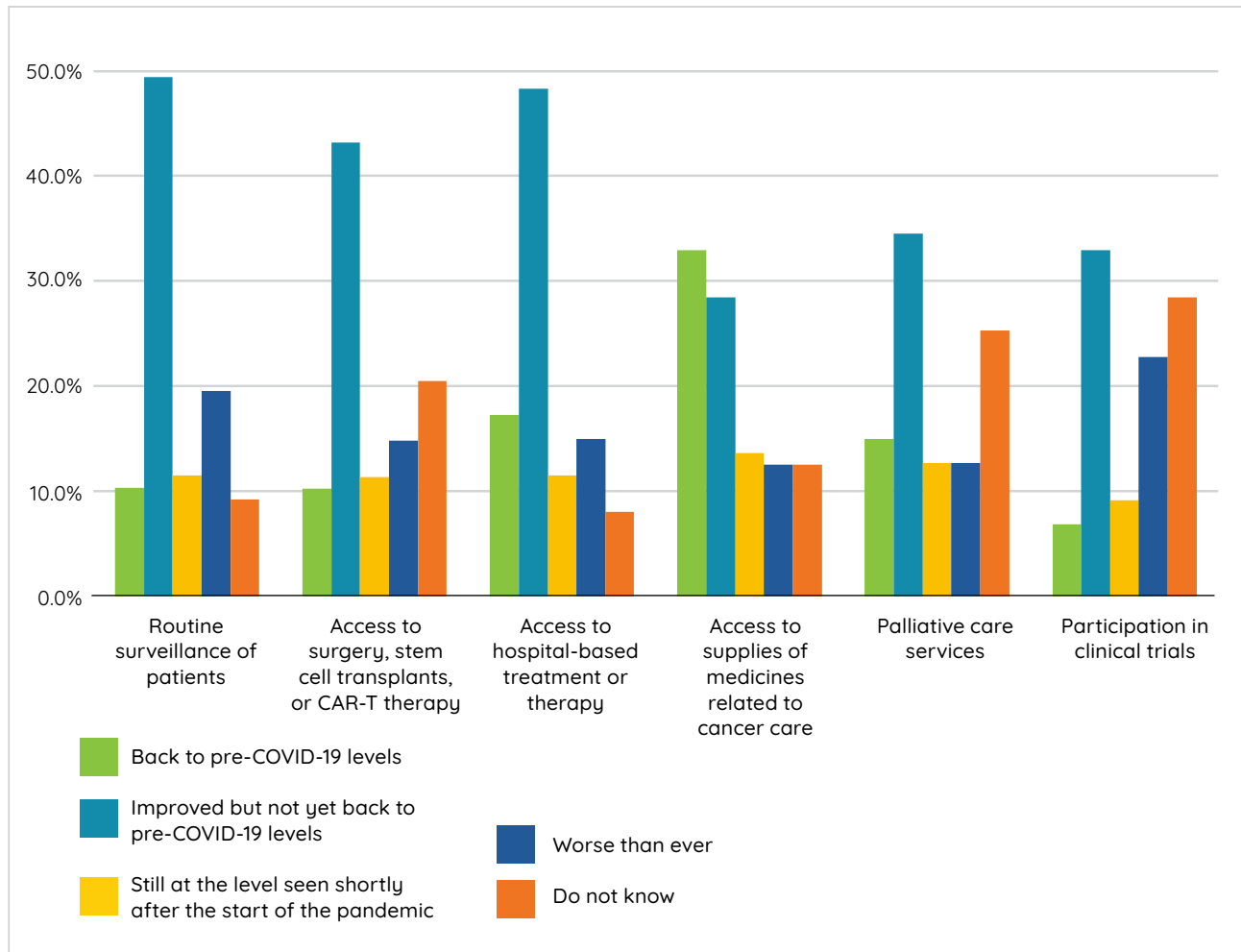


Chart 9: To what extent are the following categories relating to treatment still an issue in your country (n=89)



Concerning the various issues relating to treatment there was a similar proportion of 'worse than ever' (range 12.6–19.5%) apart from access to clinical trials (22.7%), but the return to pre-pandemic levels of access to care is still very low (range 6.8–17.2%).

One in four respondents said that treatment protocols had not been altered as a result of COVID-19 (25%), just under one in ten reported they had been changed with a positive effect (9.5%), and just under two in ten said they had been changed with a negative effect (17.9%). The remaining responders did not know. Over a third of respondents reported that cancer care guidelines have been changed more than once (34.5%), but there is positivity in that 80% of respondents said that the latest set of

guidelines are adequate and clear, at least to some extent. Some of the changes included switching to oral treatments that would limit time in the hospital and an increased use of virtual appointments for follow up.

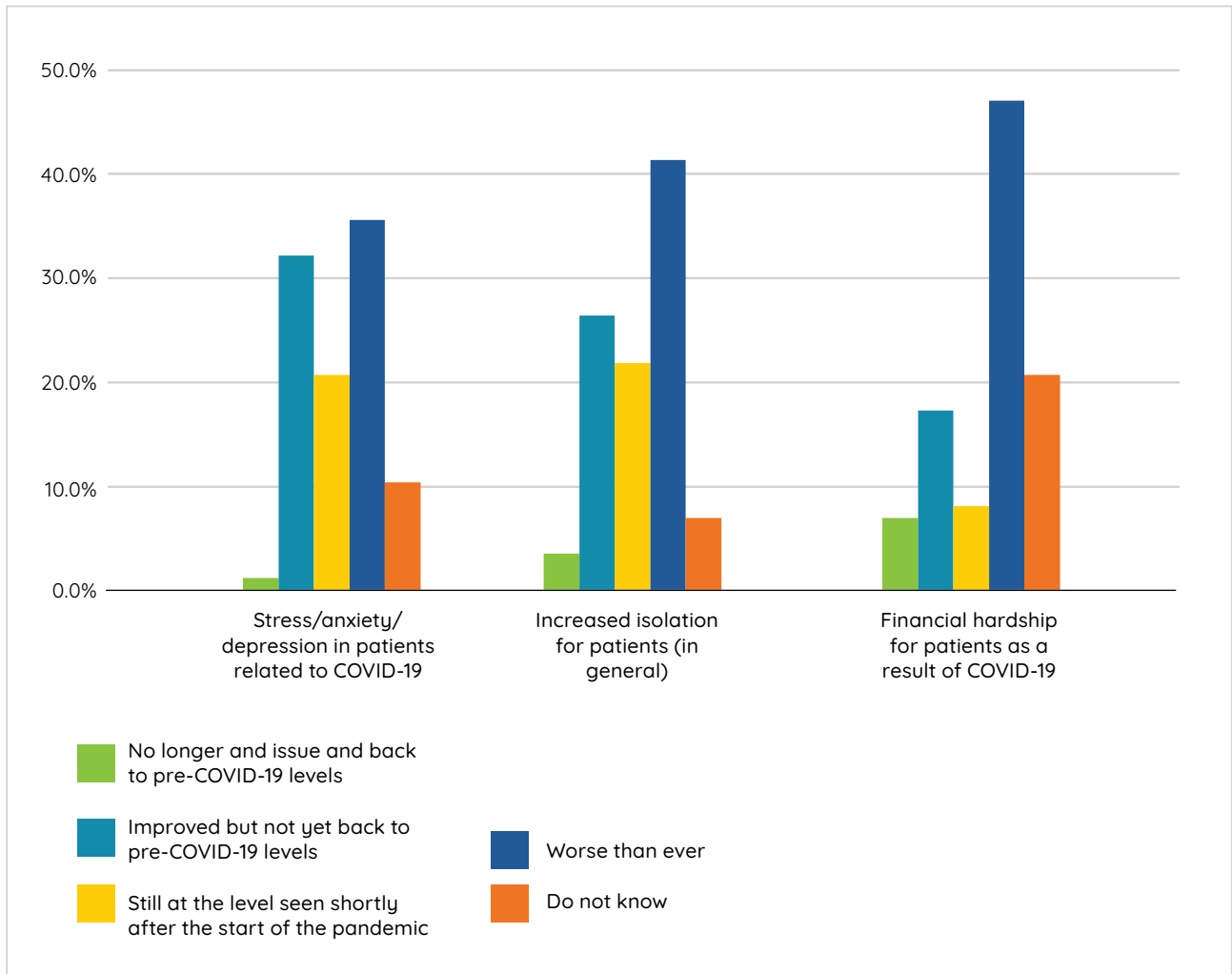
It is clear that, whilst there has been some improvement, there is still much progress to be made before cancer diagnosis and treatment returns to pre-pandemic service levels.

One respondent said that those from disadvantaged backgrounds are suffering disproportionately.

When asked about the impact of the pandemic on patients, a bleak picture emerges. Almost half said they believed patients to be facing greater financial hardships as a result of the pandemic (47.1%).

Four in ten reported that levels of patient isolation were worse than ever (41.4%) and over a third (35.6%) said levels of patient stress, anxiety and depression were worse than ever.

Chart 10: The impact of COVID-19 on cancer patients (n=87)



SHAPING THE FUTURE

Over half of the respondents to this survey have been involved, formally or informally, in discussions with other cancer and broader health charities, healthcare professionals, policy makers and politicians about how best to manage cancer care during the course of the pandemic and beyond.

Between a quarter and one-third are doing so on a formal basis (range 26.5–35.3% across the categories) and a further quarter to a half on an informal basis (range 23.5–48.8%). Most commonly, organisations have been in discussion with healthcare providers and professionals.

Only one in four have been involved in formal consultations at a national or regional government level (23.5%, from 15 mainly high-income countries).

When asked if they felt that policy makers and those leading their health infrastructures had learnt sustainable lessons from COVID-19 in relation to cancer care, 10.5% said yes, and 39.5% said yes to some extent. However, a third (33.7%) said there was a real danger of mistakes being repeated.

“My biggest concern is that we have not been able to fully mitigate the brutal impact of the pandemic on patients. My fear is that many will have died without being diagnosed or receiving any treatment, and many more will have died due to radical changes in the treatment pathway. This is the true tragedy of the impact on the pandemic on people with cancer.”

“The Government does not seem to take the needed measures in relation to taking care of cancer patients at all. We are in a deep political, social, medical and healthcare crisis.”

When given the choice to rate how the pandemic had impacted their ability to carry out their work, just six out of 54 organisations gave a score of 10 or below out of 100. Lower scores indicated that the impact of the pandemic had not been so severe. The average score was 54, demonstrating the significant challenges faced in the last twelve months.

Their most pressing concerns related to fundraising (45% of 70 responses), the impact on patient support services (21.4%) and the lack of face-to-face patient contact (18.6%).

Regarding advice to other organisations, fewer than one-third of respondents offered suggestions.

“Embrace digital! We hosted our annual patient conference online and saw registration triple. We reached patients who normally would not be able to attend. We’ve also been innovative with digital fundraising campaigns. One of our events raised more online than the usual in-person event, which was a huge achievement. We launched an online advocacy network of people who boost our social media advocacy efforts.”



“We trialled lots of digital and virtual activities ... whilst as a whole they didn’t achieve the same levels of income, we were surprised at some of the successes and it continued to keep up engagement with our supporters. We found that the small numbers of fundraisers who raise large amounts of money, e.g. in memory of someone, still needed some offering to enable them to raise these sums. One of our events – a walking event – raised as much as it did as a physical event. Lessons learnt: keep asking; trial quick and move on; link fundraising to themes of how people are feeling and what they are doing.”

CONCLUSION

Our first survey of June 2020 showed a disturbing picture of the then-current and projected challenges faced by charitable organisations who provide a wide range of services for cancer patients and their community, including funding of research and health professional education.

Six months on, little has improved. The majority of organisations are providing essential services – often adapted to the online environment – with reduced budgets, staff and volunteers, for a patient population whose needs in terms of support and information have increased significantly.

One in ten organisations have had to pause their services temporarily and it is not clear how many of the original survey sample may have had to close permanently. Looking forward this is a serious threat to the charitable and not-for-profit sector as there are few signs of reprieve regarding an improvement in income and/or a reduction in the demand for patient services, as inevitably many more patients will have delays to diagnosis and challenges accessing the best possible care. The ongoing impact on current and future research activity, including the impact of the research community, threatens much-needed progress, particularly for rarer forms of cancer.

The determination of many of the organisations represented here is incredibly high. Many are trying to embrace the few positives that have arisen from the pandemic in terms of rethinking services, models of engagement, and increasing reach with patients and their families and caregivers. However, this comes at a cost with signs of increasing staff burnout and the loss of staff to more secure jobs that are less affected by the pandemic.

For the many who rely on volunteers to deliver essential services, the crushing effect of the pandemic on patients and their families have left this once vital source of support vastly diminished.

National cancer services are already strained with the backlog of patients who have not been screened, investigated, or treated during the pandemic. Healthcare professionals are worn out and weary and many people living with cancer or experiencing cancer symptoms remain anxious about their well-being and access to safe health services.

The need for support for patient advocacy organisations has never been greater. Those who provide such vital care on the front lines are in a perilous position. The services they offer often complement or even replace healthcare services that have been displaced by the COVID-19 and are an important lifeline for patients and their families. It is imperative that emergency funding be made available so these vital organisations can continue to provide this pivotal support.

CANCER CARE CANNOT AND WILL NOT WAIT FOR COVID-19 TO PASS.

APPENDIX

International Brain Tumour Alliance COVID-19 Survey Findings

The Brain Tumour Not-for-Profit and Charity Experience of COVID-19: Reacting and Adjusting to an Unprecedented Global Pandemic in the 21st Century

The International Brain Tumour Alliance (IBTA – www.theibta.org) is also a member of the Global Cancer Coalitions Network (GCCN). At the time of the GCCN's second COVID-19 survey – which is the subject of this report – the IBTA had already completed a similar COVID-19 survey of its brain tumour not-for-profit and charitable supporting organisations around the globe. Therefore, the IBTA is providing a separate, short summary of its survey results in this document's Appendix.

An anonymous online survey was developed by the IBTA and circulated to 130 brain tumour patient organisations across the world. The 37-question survey ran from 6 May to 1 June 2020 and was comprised of a combination of categorical and qualitative, open-ended questions. In total, 77 organisations from 22 countries completed the survey. Responses to the survey were grouped into three categories: 1) organisational characteristics, 2) the impact of COVID-19 on services provided by brain tumour patient organisations, and 3) the impact of COVID-19 on financial and human resources for brain tumour patient organisations.

The IBTA's free access, full survey report on the effects of COVID-19 on brain tumour patient organisations was published in December 2020 in the Oxford University Press/Society for Neuro-Oncology/European Association of Neuro-Oncology journal, **Neuro-Oncology Advances** (<https://academic.oup.com/noa/article/3/1/vdaa166/6025169>).

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Key findings of the IBTA survey include:

- Brain tumour not-for-profits and charities around the world have experienced a substantial drop in funding. Fundraising events, conferences, and meetings were cancelled by 94% of the brain tumour patient organisations which responded to the survey, with 39% cancelling five or more events because of the pandemic.
- Brain tumour organisations were concerned about maintaining stakeholder engagement and being able to provide optimal services to brain tumour patients and their families.
- Information provided to constituents in the brain tumour community changed, with 63% of organisations stating that they were asked to provide specific information to their brain tumour communities about COVID-19.
- Nimble reactions and flexibility have been vital to brain tumour patient organisation's sustainability.
- Brain tumour patient organisations around the world have had to quickly adapt to relocating staff and volunteers to their homes and developing new methods of delivering services as well as addressing resource mobilisation.
- Lack of technological support to create webinars and online support programs, and unreliable internet in various areas of the world were challenges cited by some organisations in the survey.
- Sixty-nine per cent of brain tumour patient organisations said that in the communities which they serve, patients and caregivers were concerned about treatments being delayed, cancelled, modified or substituted because of the pandemic.
- Seventy-one per cent of brain tumour patient organisations reported that individuals in their constituencies feared contracting COVID-19 while attending doctor visits or being hospitalised. Of organisations surveyed, 69% surveyed also reported that caregivers feared they would contract COVID-19 and were concerned they would be unable to provide care to their loved ones.
- There was a growing realisation at the time of the survey that the pandemic might be prolonged and that the post-COVID-19 era might be very different in many ways from the pre-COVID-19 period.
- Qualitative responses in the survey highlighted that the pandemic also presented opportunities for some organisations to develop new relationships they had not previously imagined, finding strength through collaboration. Some organisations found ways to save money by spending differently. New ways of working to accomplish goals and achieve the organisational mission were realised.
- It is clear from the results of the IBTA's survey on "The Brain Tumour Not-for-Profit and Charity Experience of COVID-19..." that quickly reacting and adjusting to an unprecedented global healthcare crisis in the 21st century has been crucial for the viability and sustainability of brain tumour patient organisations.

The Brain Tumour Not-for-Profit and Charity Experience of COVID-19: Reacting and Adjusting to an Unprecedented Global Pandemic in the 21st Century

(<https://doi.org/10.1093/noajnl/vdaa166>) is an Open Access article distributed under the terms of a Creative Commons Attribution License (<http://creativecommons.org/licenses/by/4.0/>).

About the Global Cancer Coalitions Network Survey

This survey was developed by the World Ovarian Cancer Coalition, the World Pancreatic Cancer Coalition, the Lymphoma Coalition, the Advanced Breast Cancer Global Alliance, the Global Colon Cancer Association, and the World Bladder Cancer Patient Coalition.

The coalitions involved distributed the survey directly to their members via unique links. The survey (hosted by Survey Monkey), data analysis, and report draft were prepared by Frances Reid, Programme Director of the World Ovarian Cancer Coalition. The survey was open from 23 November to 13 December 2020.

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 only partially complete.

In order to protect the confidentiality of organisations, all identifying information, including cancer type and country, has been removed from quotes.

Each coalition will receive the raw data for their members' responses, but this will not be distributed any further. The complete data set is retained by the World Ovarian Cancer Coalition.



GLOBAL **CANCER** COALITIONS NETWORK

About the Global Cancer Coalitions Network (GCCN)

Established in May 2020, in response to concerns about the impact of COVID-19 on member organisations, the GCCN collectively represents some 750 cancer patient advocacy and support organisations who are working on behalf of over 14 million patients around the world. The network came together to share experiences and best practice, a process they have found invaluable during the pandemic, and one that they plan to continue.

The GCCN consists of leaders from the following cancer groups:

- Advanced Breast Cancer Global Alliance
- Global Colon Cancer Association
- Global Lung Cancer Coalition
- International Brain Tumour Alliance
- International Kidney Cancer Coalition
- Lymphoma Coalition
- World Bladder Cancer Patient Coalition
- World Ovarian Cancer Coalition
- World Pancreatic Cancer Coalition