GLOBAL **CANCER**
COALITIONS NETWORK

CLOSE THE LOOP:
Cancer patient organisations doing more with less

February 2026

CONTENTS

EXECUTIVE SUMMARY

This Global Cancer Coalition Network surveyed members in 2021 when the world was in the midst of the pandemic, and found worrying trends related to the healthcare patients receive and the sustainability of much needed and utilised patient organisations. Now, 5 years later, when the world is facing different, varied challenges, our latest survey shows there is still cause to be concerned.

Where organisations work

For many of the organisations responding, home-based or remote working is a lasting legacy of the pandemic with **just under half (49.2%) reporting that more staff are either home-based or now split their time between the office and home**. Staffing numbers themselves appear fairly consistent, with **82%** reporting staffing levels either equal to or higher than pre-pandemic levels and nearly half **(46.7%)** reporting having more volunteers.

Organisations' income

The vast majority of the organisations responding (**84.4%**) rely on fundraising to support their activities. While the pandemic appears to have had little lasting effect on organisations' income streams, cause for concern is the **62.8% reporting that income is either static or has fallen.** This is set against a time of high inflation in many countries around the world.

Support for patients

As with homeworking, the legacy of the pandemic is that many patient services continue to be delivered remotely. Although today organisations are better placed to strike a balance; offering services online as a means of reaching more patients while managing costs and at the same time being able to invest in a limited number of face-to-face or hybrid events. And some stress the use of phone services, serving as a vital reminder that while continuing to rise, internet access is still far from universal. Overall, demand for services is up, with **69.1% of organisations reporting that demand for services is higher today than pre-pandemic.**

Cancer research

The pandemic saw research programmes paused, reduced in scope or stopped altogether and the responses from organisations that had research programmes suggest that the impact of that is still being felt. Just **13.7%** report that they are now investing more in research compared to **31.4% who either invest less or have stopped delivering research altogether.**

82%	staffing levels either equal to or higher than pre-pandemic levels
62%	report that income is either static or has fallen
69%	organisations report that demand for services is higher today than pre-pandemic
31%	invest less or have stopped delivering research altogether

Health systems

When it comes to health systems, while there is a marked improvement in the number of respondents reporting that services have returned to normal since our 2021 report, there are still causes for concern, with significant numbers reporting services have yet to get back to pre-pandemic levels. And respondents expressed concerns that should a future pandemic strike little would be different – only **14.9%** felt that those in charge would do a better job and **one third felt that policy makers and those running health services were at risk of making the same mistakes.**

Looking to the future

Recovery from the pandemic has been a slow process for many organisations. **51.1% of respondents said that COVID-19 had a negative impact on their organisation** and when asked on a scale of 1–5 the extent to which they had recovered, the average response was 3. But the passion and the focus of organisations comes through when asked about their priorities for the future, with patients at the heart of everything they do.

Very high HDI countries

28% of organisations reported not having sufficient income to meet patients' needs.

Low, medium or high HDI countries

81% of organisations operating in countries with either a low, medium or high HDI classification.

42% of organisations said that their income is not high enough to meet patient needs.

47% reporting having more volunteers today

FOREWORD

When COVID-19 hit in 2020 the impact on cancer patient organisations was immediate. The patient organisations we work with found themselves facing delays in screening and diagnostics, or unable to access vital treatment. Patient organisations themselves saw their funding hit, staff support services and events moved online and research programmes put on hold.

The Global Cancer Coalitions Network was formed in repsonse to the pandemic. We collectively represent some 750 cancer patient advocacy and support organisations who are working on behalf of over 14 million patients around the world.

Our first piece of research tracked the immediate impact of COVID-19 on cancer organisations. The report 'COVID-19: Impact on Cancer Patient Organisations Worldwide in 2020' revealed that two thirds of organisations relying on fundraising had seen their income fall and the number of staff had likewise shrunk, while at the same time demand for services was up. There was mass disruption to health systems and research was badly hit, with just a third of organisations delivering research programmes reporting these as unaffected.

Five years on, this report aims to see to what extent cancer organisations and the patients they support have been able to move on from the pandemic while navigating through a more complicated and political world. It also takes stock of the lasting legacy of COVID-19 for cancer patient advocacy and support organisations.

We hope it will act as a useful tool for our members and make the case to policy makers that when it comes to cancer services challenges remain far from over.

Clara Mackay

Chief Executive Officer,
World Ovarian Cancer
Coalition and Co-Chair
Global Cancer Coalitions
Network

Alex Filicevas

Executive Director,
World Bladder Cancer
Patient Coalition and
Co-Chair Global Cancer
Coalitions Network

METHODOLOGY

Our research

We carried out a survey which was distributed via Global Cancer Coalition Network members and was live from 23 January 2025 to 10 March 2025. Once closed, duplicate entries were removed (taking either the most complete response or the response from the most senior member of the organisation) leaving a total of 104 responses.

A total of **4 interviews were conducted** to supplement the survey research and organisations were recruited from survey responses with participants from **Brazil, India, America** and **Australia.**

Quotes used in the report have come from the survey and include cancer type and continent to give a sense of the survey's breadth while preserving organisations' anonymity.

Not all sections of the survey were relevant to all organisations and table 1 shows the number of responses by report chapter.

Table 1: Response rates by chapter

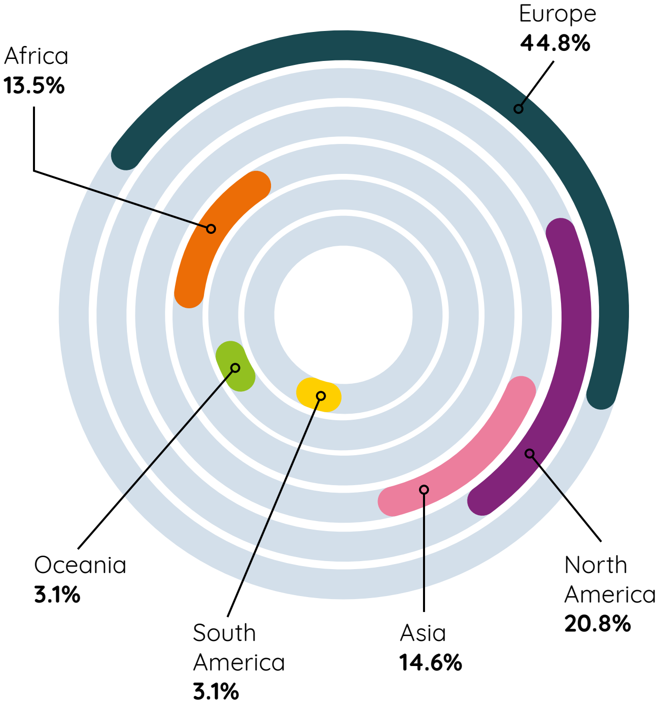
CHAPTER	RESPONSES
How COVID-19 changed where organisations work	95
The lasting impact of COVID-19 on organisations' income	81
How COVID-19 reshaped support for patients	71
How COVID-19 continues to affect cancer research	50
The long-term impact of COVID-19 on health systems	87
Looking forward	88

The organisations taking part

104 organisations took the survey. As our focus was the difference pre and post COVID-19, eight were excluded due to not having been in existence prior to the pandemic. The data used in this report is based on the answers the remaining organisations provided.

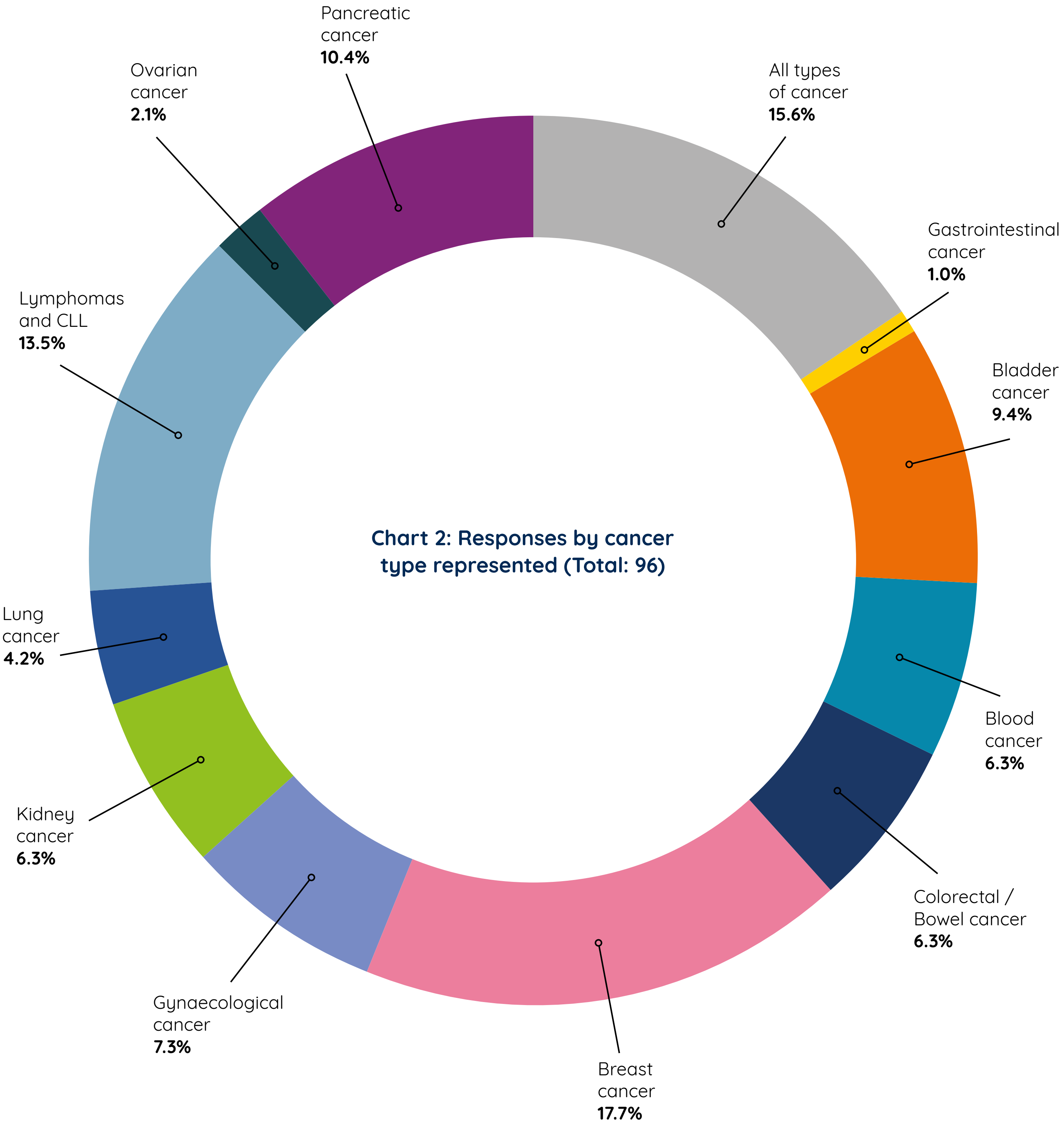
Organisations from **45 countries took part in the survey** with the distribution by continent set out in **chart 1**.

Chart 1: Responses by continent (Total: 96)



In terms of the Human Development Index (HDI) for the home country of respondents, **8 responses came from countries with a low HDI status, 7 from nations with a medium status, 10 from states with a high status** and **71 from countries with a very high status.**

Chart 2: provides a breakdown of the different cancers represented by the patient organisations taking part.



Finally, organisations were asked to describe their size.
49 described themselves as small, **37** as medium and **10** as large.

CHAPTER ONE:
HOW COVID-19 CHANGED WHERE ORGANISATIONS WORK

For Global Cancer Coalition Network members, home or hybrid working appears here to stay. In our 2021 report, **half of respondents (50.5%) reported that staff and volunteers were currently working from home.**

That trend can be seen to have carried through to today with **49.2% of organisations reporting more staff are either homebased or split their time between the office and home** (hybrid working), than prior to the pandemic.

When those that offered home or hybrid working were asked for their reasons why, **58.5% of organisations said it helped with recruitment and retention and 51.2% pointed to the benefit of lower or no office costs.**

However, home-based or hybrid working is not without its challenges. **50.0% of those offering it cited maintaining organisational culture as a challenge, 43.5% identified challenges with training and integrating new staff and 37.0% said managing staff performance was hard.**

46.7% **reporting having more volunteers today**

Of those organisations responding, **11.6% were run entirely by paid staff, 52.6% by paid staff and volunteers and 35.8% by volunteers only.** When asked about staffing levels pre and post pandemic, roughly half **(47.5%) of organisations said they had the same number of staff, 34.4% said they had more and 14.8% had fewer.** There was a bigger shift when it came to volunteers, with **46.7% reporting having more volunteers today than pre-pandemic, 32.6% the same and 18.5% fewer.** [1]

Quotes

“Hybrid working helps us; we can address a larger number of patients and their needs, especially considering those in remote regions. It also helps us reach patients who may not be able to come to the office due to their health or transportation issues.”

Blood cancer organisation, Europe

“Homeworking has become the expectation among staff following the culture shift required by the pandemic.”

Breast cancer organisation, Oceania

“We have a virtual staff call every Monday morning, which brings everyone together and we also plan a staff retreat every year where the entire team comes together for strategic planning and connection”

Lymphoma organisation, North America

---

[1] Numbers don’t total 100% due to a small number of respondents selecting ‘other’.

Taking a closer look

Finding the right role for volunteers

V Care is a patient care organisation working with patients and caregivers of all ages and all diagnoses in India. It started as an emotional support group after its founder, Vandana Gupta underwent cancer treatment in the 1990s – back then there was no Google or smartphones and despite having a masters in English Literature, even she found it hard to understand the language used by doctors. She thought how much more challenging it must be for people coming to the hospital who didn't even speak the local language to begin with.

Prior to the pandemic, V Care's core activity was **volunteers visiting patients in hospital.** But **many volunteers were over 50 years old**, and their family members weren't happy with the **risk of them going into hospitals during COVID-19**. This saw the organisation shift, relying more on **paid patient navigator roles** and many of the original volunteers haven't returned.

However, the organisation does **still recruit professional volunteers.** Opportunities are built around the skills and interests of individuals. Volunteer **recruitment takes place largely by word of mouth and careful consideration** is given before taking new volunteers on, recognising the investment in training volunteers up.

It is made clear to volunteers that **they are expected to be reliable** – even if just volunteering one day a month, **the organisation has to be sure that they can rely on them being there** for that day as opposed to people just turning up as and when they want. It is also **made clear to volunteers that the role can often involve dealing with difficult circumstances**, something not everyone would be comfortable with. For those not able to take on more formal roles, other opportunities are found, such as **community fundraising or delivering ad hoc workshops.**

CHAPTER TWO:
THE LASTING IMPACT OF COVID-19 ON ORGANISATIONS' INCOME

84.4% of respondents are reliant on fundraising to support their activities.

Our 2021 report highlighted the immediate impact COVID-19 had on cancer organisations finances; **67.4% of those organisations reliant on fundraising had experienced a drop in income** with almost all attributing this to the pandemic.

The areas worst affected were those immediately impacted by restrictions on activities out of the home – respondents to our previous survey reported their own **fundraising events were hit hardest (82.1%) followed by community fundraising (70.9%) and public collections (47.0%)**.

However, we asked those organisations responding to the latest survey to list their top 3 sources of income prior to the pandemic and their top 3 after and as tables 2 and 3 show, the long-term impact has been minimal.

Table 2: Sources of fundraising that featured within organisations' 'top 3' pre-pandemic

Pharmaceutical company support	39	50.0%
Organisations own fundraising events	35	44.9%
Grants	24	30.8%
Major donors	23	29.5%
Corporate support (non-pharmaceutical)	18	23.1%
Community fundraising	16	20.5%
Postal or online donations	15	19.2%
Public collections	14	17.9%
Direct mail campaigns	3	3.8%
Membership fees	3	3.8%
Payroll giving	2	2.6%
Other	3	3.8%
Total	78	

Table 3: Sources of fundraising that featured within organisations' 'top 3' post pandemic

Pharmaceutical company support	40	51.3%
Organisations own fundraising events	32	41.0%
Grants	24	30.8%
Major donors	24	30.8%
Corporate support (non-pharmaceutical)	22	28.2%
Postal or online donations	16	20.5%
Community fundraising	14	17.9%
Public collections	13	16.7%
Payroll giving	4	5.1%
Direct mail campaigns	3	3.8%
Membership fees	1	1.3%
Other	4	5.1%
Total	78	

Looking solely at the source of income organisations ranked as 'top', pre-pandemic **almost a third of organisations (31.5%) gave pharmaceutical funding as their top source of support, 16.4% listed their organisation's own fundraising events, 13.7% gave grants and another 13.7% gave major donors as their top source of income.**

Post pandemic, **28.8% list pharmaceutical funding as their top source of income, 17.8% listed grants, 15.1% cited major donors and organisations own fundraising events dropped to 13.7%.**

When asked whether income today was higher or lower than before the pandemic, the picture was mixed, but overall **62.8% reported income was either static or had fallen (with that figure rising to 71.8% among organisations describing themselves as small) and just 35.9% had seen their income grow** over the 5 year window.

The implications of this can be seen in the **42.3% of organisations who say that their income is not high enough to meet patient needs.**

Within this there is a stark contrast according to HDI status; **28.1% of organisations working in countries with a very high HDI score reported not having sufficient income to meet patients' needs, compared to 81.0% of organisations operating in countries with either a low, medium or high HDI classification.**

Despite these challenges, organisations remain somewhat optimistic about their long-term finances. **When asked to rank on a scale of 1-5 how optimistic they were that they would have sufficient funding to meet patients' needs in 5 years' time, the average response was 3.**

28% of organisations working in countries with a very high HDI score reported not having sufficient income to meet patients' needs

81% of organisations reported not having sufficient income to meet patients' needs (operating in low, medium or high HDI classification)

42% of organisations said that their income is not high enough to meet patient needs.

Quotes

"Inflation is becoming an increasing burden because all the prices went up in our country so our expenses have also grown and they will continue to grow."

Breast cancer organisation, Europe

"The lack of a donation culture in [country] among both companies and the general public makes it difficult to obtain funds."

Ovarian cancer organisation, Asia

"The current government's decision to increase employers' taxes and the minimum wage is having a hugely detrimental effect on the charity."

Lung cancer organisation, Europe

"The government removed fuel subsidies, and since then, inflation has gone up by almost 28%. Staff salaries are no longer enough; we have to keep everyone at home until we are able to get enough funds to increase salaries."

Breast cancer organisation, Africa

"Organisational sustainability is scary with low donations and poor global funding. There is much funding for HIV/AIDs and many infectious diseases, but for cancer, it is almost zero. There is a need for newer strategies for cancer funding and support for organisations in low-resource regions."

Breast cancer organisation, Africa

Taking a closer look

Building supporter networks

Shujaa is Swahili for warrior and the Shujaa Cancer Foundation (SCF) supports cancer patients and survivors in Tanzania.

SCF have identified that the biggest challenge faced by most of the cancer patients and survivors they work with is financial and they have established their “Rudisha Tabasamu / Bring back the smile” programme to try and address this.

They are asking for people to sign up as friends of the organisation and to make a monthly donation of at least TSH10,000 to help fund the programme and in return to receive updates on the programme and the support it offers. They have recruited to the campaign largely by word of mouth, going out to people they have supported alongside family and friends of staff members.

The personal touch

The Cutaneous Lymphoma Foundation (CL Foundation) is based in the United States. It represents patients globally with a very rare form of lymphoma that presents differently and has different diagnostic and treatment pathways to other types of blood cancer.

Fundraising can be a challenge for a number of reasons. Firstly, due to the disease itself – patients cover a wide spectrum; for those who are diagnosed with early stage that typically doesn’t progress, the engagement is lower, with patients seeing it as a long-term condition they simply live with and as a result, not engaging with the support on offer from patient organisations.

Among those for whom the disease is more challenging, there’s a smaller patient population which, while engagement may be higher, is more dispersed. This means it doesn’t work to organise a fundraising event like a local run or a gala as the distances involved for supporters to attend would be too great.

The nature of the disease can also make it hard to appeal to external funders. It predominantly affects older people and manifests as a visible skin condition where often patients do not want to be public about their disease. It doesn’t have the same emotional pull as a cancer affecting children or young mums might. It’s also hard to explain, making it difficult to inspire those not affected by the disease to engage in fundraising events.

The focus is therefore on individual giving and despite not having a dedicated fundraising lead, the CL Foundation’s team is trying to develop their stewardship of donors and in part are turning their small size to their advantage. For example, their top 50 donors receive personal thank you letters from the board, something less likely to happen in larger organisations. The current priority is to encourage individuals who give consistent annual donations to move to monthly giving; this might not have a huge impact in terms of total donations but consistency in giving would help with operational planning. The team’s perseverance in developing their individual giving fundraising stream is paying off, with donations having steadily risen over the past decade.

CHAPTER THREE:
HOW COVID-19 RESHAPED SUPPORT FOR PATIENTS

Our 2021 report found that **41.9% of organisations stopped delivering face-to-face support during the pandemic and 37.2% developed new online support services.** Fast forward to today and it's possible to see that some, although not all, of these changes remain.

77.2% of the organisations responding deliver patient facing services and demand is rising with 69.1% of organisations reporting that demand for services is higher today than pre-pandemic with that figure rising to 78.9% among organisations from low, medium and high HDI countries.

We asked what permanent changes to services had resulted from COVID-19. A significant number of responses made some reference to online activities, reasons for this varied but included:

- Improved geographical reach, meaning organisations can reach more patients or access patients in remote areas that they may have previously struggled to support.
- Better accessibility for some patients, for example those needing specialist communication equipment or for whom travel is difficult.
- Easier for clinical experts to participate as they can join events remotely and fit participation around clinics.
- Resources can be available indefinitely, for example webinars can be recorded and then made available indefinitely on organisations' websites.
- Demand from patients.
- Lower costs as online events remove the need for venues and travel.
- More effective use of staff time by removing travel time.

Below are some of the responses from individual organisations:

"Nutritional counselling, genetic information and education programs have switched mainly online as this is easier for our lecturers who are mainly oncologists and also then lectures are available on a national level for all our beneficiaries who are interested."
Breast cancer organisation, Europe

"We have seen a considerable decrease in the number of patients who physically attend our events/meetings after the pandemic."
Bladder cancer organisation, Europe

"We introduced webinars as opposed to physical meetings which were a great success as they are available both online and for looking at afterwards"
Lymphomas and CLL organisation, Europe

"We did not offer zoom or YouTube before the pandemic but decided to continue offering it due to the high demand from patients living in rural areas."
Ovarian cancer organisation, Asia

Many organisations also stress that they take a hybrid approach:

"We offer more programs than prior to the pandemic and the majority are offered online. We have also introduced a patient education session where we travel to 2 different cities per year to offer in-person support and education."
Bladder cancer organisation, North America

“During the pandemic, we decided to maintain several services online. These services are now offered both in-person and remotely, and we also provide hybrid options to meet the diverse needs of our clients. By applying these methods, we can better respond to our patients’ preferences and ensure that everyone can receive the necessary support and information in the most convenient way.”
Blood cancer organisation, Europe

“We haven’t opted for any service to be permanently online however, we have some online to reach those we cannot reach otherwise.”
Breast cancer organisation, Africa

Respondents were also asked for examples of ways in which technology has helped in delivering their services:

“Cancer can affect vision and hearing, and patients can end up with severe mobility impairments due to CNS tumours. As a result of offering meetings online, our access has expanded to those who can better access support using their customised online environments set up in their home.”
Pan cancer organisation, Europe

“Our support group went from meeting live to zoom and doubled in size.”
Gynaecological cancer organisation, North America

And while access to the internet continues to grow, the International Telecommunication Union gives the **proportion of the population using the internet (in all its forms, broadband or mobile) at just 68%. While in high income countries that figure rises to 93%, for low income countries it’s just 27%**.[2] Several organisations mentioned delivering services via phone alongside online or face-to-face support.

“Telephone navigation worked well during the pandemic; we have continued with it and patients really appreciate it”
Pan cancer organisation, Africa

“We increased our telephone and online support during COVID-19 and this has remained as a support option.”
Lung cancer organisation, Europe

Finally, the response from one organisation indicates what a future path for services might look like for others. As more and more treatments can be taken at home, the relationship between patients and healthcare providers is changing and this is pushing demand for services from patient organisations.

“The greater use of oral treatments sees people more remote from health services and increasingly turning to external organisations for support.”
Breast cancer organisation, Oceania

---

[2] International Telecommunication Union. Available at: https://data.worldbank.org/indicator/IT.NET.USER.ZS [Accessed 28/05/2025]

Taking a closer look

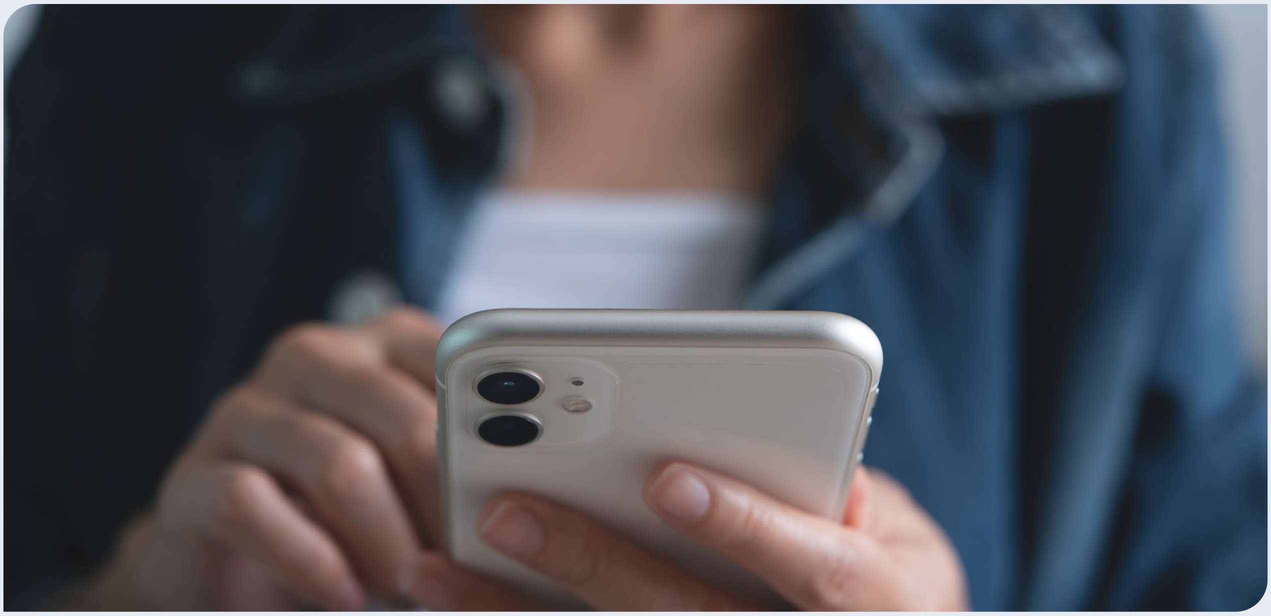
Reaching more patients

Association Kraujas in Lithuania is a blood cancer organisation that brings together patients, their families and clinicians. During the pandemic, remote events became an essential part of their activities, allowing them to reach a wider audience and maintain community connections. Events, such as virtual seminars and conferences, enabled them not only to keep in touch with existing supporters but also to attract new participants who may not have attended physical events before. Hybrid conferences, combining both in-person and remote participation options, provided flexibility and convenience, allowing attendees to choose the format that best suited them.

Remote assistance for patients, particularly onco-psychological support, became extremely important. By providing psychological support remotely, they have been able to reach those who might not have the opportunity to attend in person. This has allowed patients to receive the necessary help from the comfort of their homes, reducing the stress and anxiety associated with travel and in-person visits.

Additionally, they are currently developing a mobile app which will provide patients and their families with easy access to specialists and will allow them to view their treatment plan. This initiative aims to enhance the overall patient experience and foster greater engagement in the treatment process.

Finally, social media has also played a significant role in their activities. By utilising platforms such as Facebook and Instagram, they have been able to quickly and effectively inform the community about upcoming events, share success stories, and strengthen community engagement. Social media has become not only a communication tool but also a means of building community, allowing people to engage and support their initiatives.



CHAPTER FOUR:
HOW COVID-19 CONTINUES TO AFFECT CANCER RESEARCH

56.2% of respondents had research programmes live at the start of the pandemic. Looking back at the impact of COVID-19, **21.6% reported that it resulted in research programmes being paused,** 27.5% that they had a reduced scope and 5.9% that they were stopped altogether.

In terms of how this translates into research programmes today, **just 13.7% of respondents reported that they now invest more in research,** whereas **43.1% invest about the same, 27.5% less and in 3.9% of cases their research programme no longer exists.**[3]

Quotes

> “We invest less in research today due to a lack of funding, especially as it’s a small country with the same people to ask all the time.”
>
> **Pancreatic cancer organisation, North America**

> ‘If a campaign focuses on research donations, we will see an increase in support, however it then restricts funding and limits our administrative and programming support.’
>
> **Bladder cancer organisation, North America**

Taking a closer look

Time to think

The Leukaemia and Lymphoma Society of Canada was formed by five women sat around a kitchen table in the 1950s who decided to do something about the lack of funding for leukaemia research. While the organisation’s focus has broadened over the years, widening to include all blood cancers and with a strong emphasis on support for patients, research remains at its core.

However, when COVID-19 struck the research programme had to be paused for a year. But this also allowed time to reflect on the programme and what it delivered. As a result the organisation decided to move towards a model focused on funding partnerships, rather than trying ‘to do everything’ themselves. This has allowed them to fund a greater number of research initiatives for roughly the same investment as previously. In fact, they’ve been able to effectively double the number of projects funded.

Therefore, while the immediate impact of the pandemic was a negative one, the space to think it created led to a revived research programme with a broader reach than its predecessor.

---

[3] 11.8% selected ‘other’

CHAPTER FIVE:
THE LONG-TERM IMPACT OF COVID-19 ON HEALTH SYSTEMS

Respondents were asked to report the extent to which diagnostic services and treatment have returned to normal post pandemic (with a small number reporting they hadn't been affected in the first instance). There is marked improvement from our 2021 report, where, when asked the extent to which diagnostic services and treatment had returned to normal against the same categories as those below, all scores bar one (access to medicines at 33.0%) were below 20%, meaning fewer than one in five respondents had reported a return to pre-pandemic levels.

Chart 3a shows that improvements are being seen across diagnostic services, especially in terms of people seeking help for possible symptoms.

However, the number of respondents reporting services had returned to normal only once nudges past 50%, indicating many services are still struggling to recover five years on from the pandemic.

Chart 3b shows this more clearly by splitting responses simply between those reporting services have returned to normal and those not (along with those saying they don't know). It makes it clear how much work remains to be done to regain ground lost during COVID-19.

Chart 3a: The extent to which key diagnostic services have returned to normal post COVID-19 (Total: 86)*

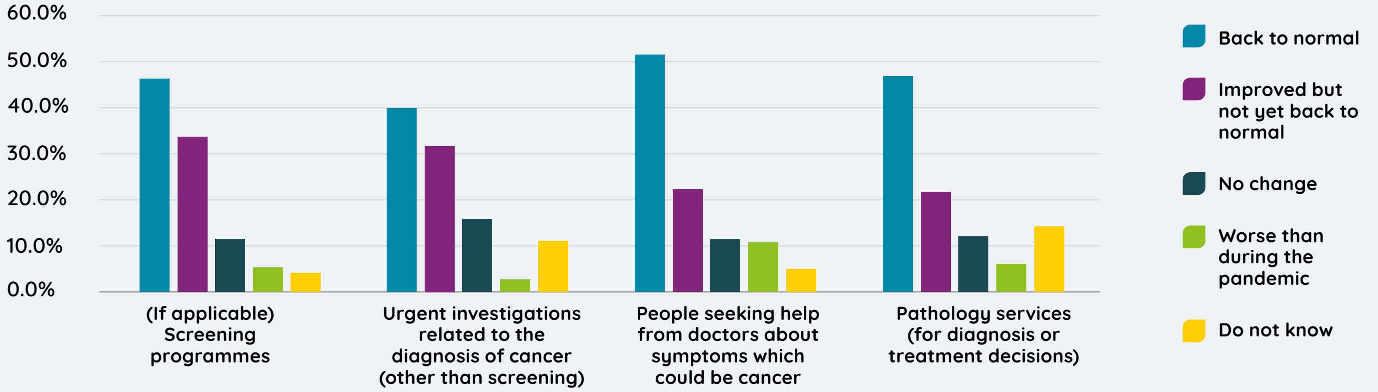
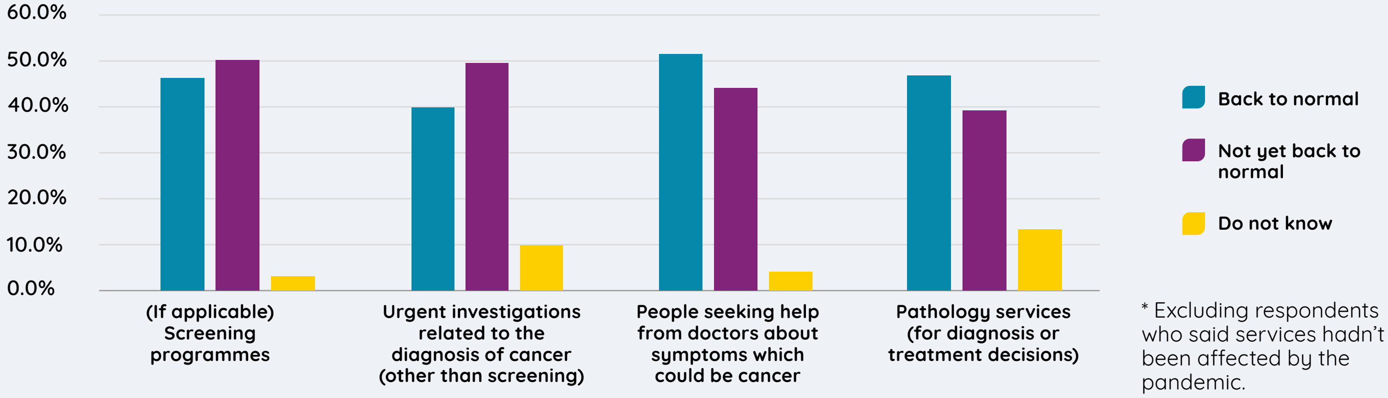


Chart 3b: The extent to which key diagnostic services have returned to normal post COVID-19 (Total: 86)*

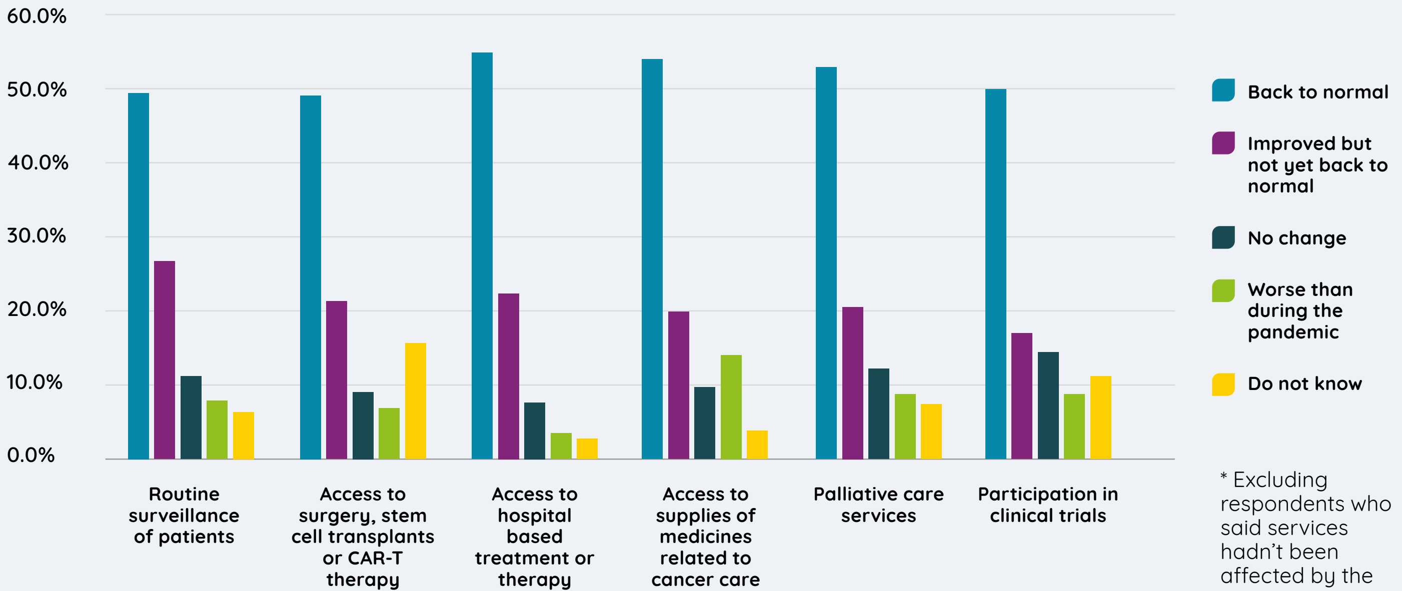


* Excluding respondents who said services hadn't been affected by the pandemic.

Turning to treatment, as chart 4a shows, there is a similar pattern of improvement with a marked increase in the number of respondents saying services had returned to normal in comparison with our 2021 report.

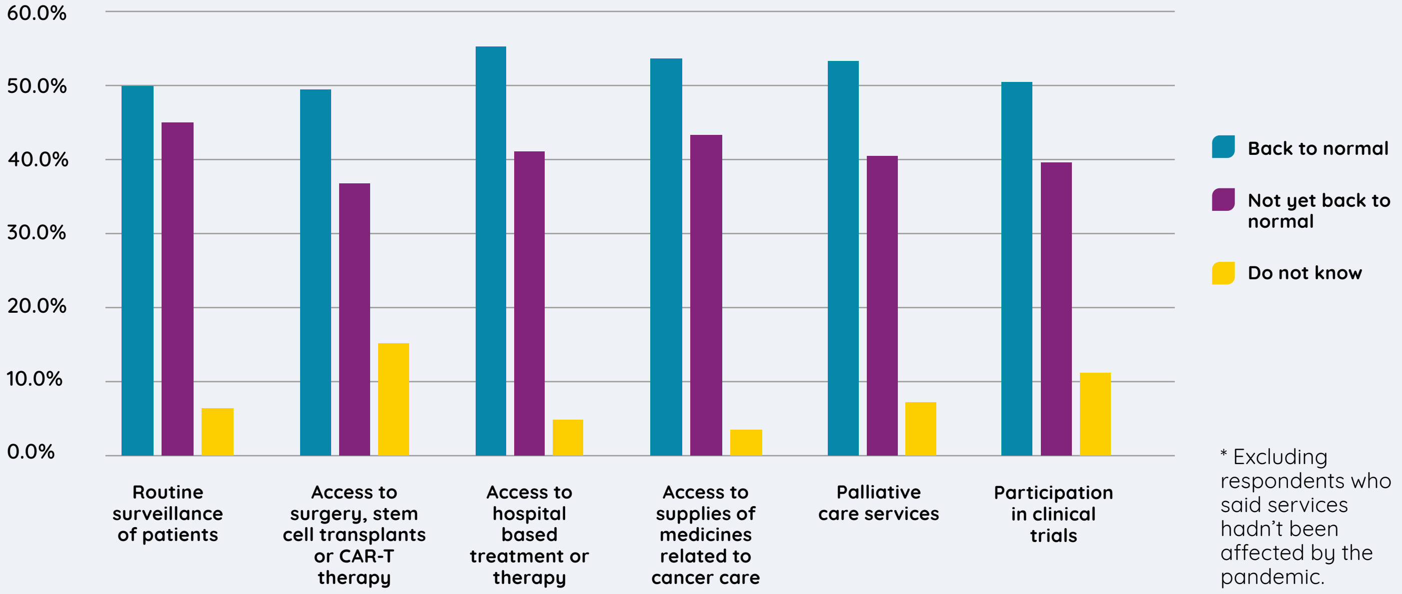
However, as with diagnosis, by grouping all those respondents who indicated that, even if improving, services were not yet back to pre-pandemic levels, chart 4b shows that across all areas significantly more remains to be done for services to be restored to pre-pandemic levels.

Chart 4a: The extent to which treatment has returned to normal post COVID-19 (Total: 86)*



* Excluding respondents who said services hadn't been affected by the pandemic.

Chart 4b: The extent to which treatment has returned to normal post COVID-19 (Total: 86)*



* Excluding respondents who said services hadn't been affected by the pandemic.

Given the delay in services getting back to pre-pandemic levels, it is concerning that organisations have not been more closely involved in work to restore these. Table 4 shows that, while **at least half have discussed the issue with other charities (56.3%) and the same number have had discussions with health care providers (56.3%)**, when it comes to engagement with policy makers, **just a third (32.2%) have been involved in government led consultations.**

Table 4: Involvement in discussions about the recovery of cancer services post pandemic

We have had discussions with other cancer charities	49	56.3%
We have had discussions with other health charities (not just cancer)	25	28.7%
We have had discussions with health care providers and/or professionals	49	56.3%
We have been involved in national or regional consultations (government led)	28	32.2%
Not applicable – cancer services weren't impacted by the pandemic	2	2.3%
We have not been involved in any discussions about the recovery of cancer services	13	14.9%
Don't know	4	4.6%
Other	3	3.4%
Total	**87**	

This delay in services returning to normal and the failure in many cases to involve cancer organisations in this, can be seen in respondents' confidence that their 'country's policy makers and those in charge of health services would now be better prepared for a future pandemic in relation to cancer care'. **Chart 5 shows that 33.3% felt these decision makers were at risk of making the same mistakes.**

Finally, respondents were asked by how many years they felt the pandemic had set back diagnosis and treatment in their country. The average response was 3 years. However, there is a clear split according to countries' HDI status. **Respondents from countries with a very high HDI status reported on average a 2 year delay but this rises to 4 years among countries with a low, medium or high status.**

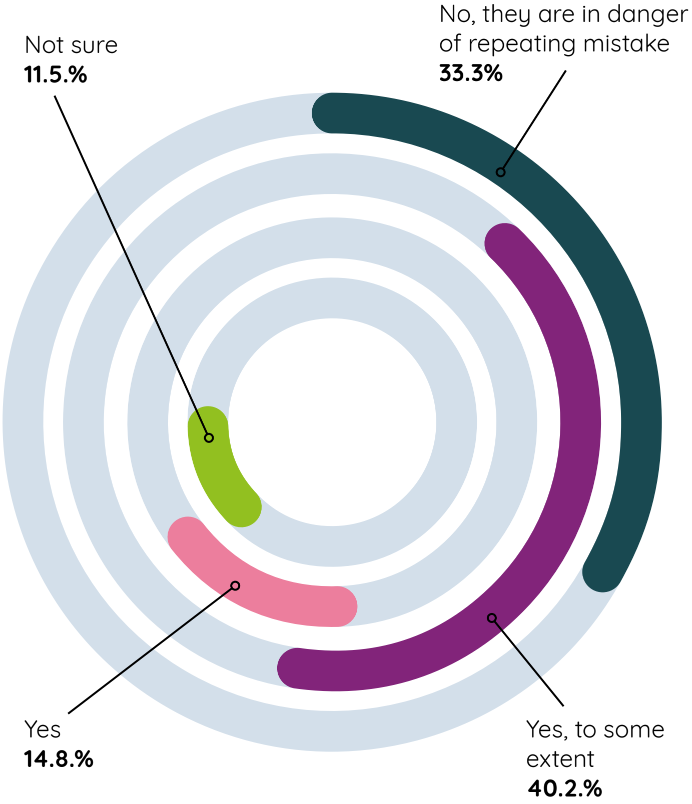


Chart 5: Extent to which a country's policy makers and those in charge of health services would now be better prepared for a future pandemic in relation to cancer care (Total: 87).

Quotes

> ‘There are long waiting lists for the follow up of breast cancer patients once they have finished treatment.’
>
> **Breast cancer organisation, Europe**

> ‘Cancer care in general has many issues that started before COVID-19 and got worse during COVID-19, including the lack of personnel and an overburdened health system.’
>
> **Breast cancer organisation, Europe**

Taking a closer look

Fighting for change

Oncoguia is Portuguese for cancer guide and that is the reason this organisation, based in Brazil, was first established in 2003 to address the gap in reliable information available for cancer patients.

Over time Oncoguia evolved from focusing just on patient information to taking on a broader role in patient advocacy. In particular, work has been focused on trying to address late stage diagnosis, with more than half of cancers in Brazil diagnosed at a late stage. Brazil also has a split health system with a stark divide between private and public health services, then again within public services themselves due to the way cancer care is financed.

To help address this, Oncoguia and other institutions have been campaigning for a new law to guarantee access to services, specialists and technologies. The process involved the designing of the initial text of the legislation and then working with parliamentarians to get it introduced and discussed. This was difficult as the advocacy work took place during and after the pandemic, but as Oncoguia had already formed good working relationships with key parliamentarians, the switch to meeting online was easier.

It took eighteen months of work, but the National Policy for Cancer Prevention and Control finally received approval in 2023. This new legislation will take much of what is currently only guidance for cancer pathways and turn it into mandatory protocols.

CHAPTER SIX:
LOOKING FORWARD

Respondents were asked whether **COVID-19 had had a negative impact on their organisation with 51.1% responding that it had.**

There is a split according to HDI status. **62.5% of organisations in countries with low, medium or high HDI classification reported COVID-19 having a negative impact on their work compared to 46.9%** of those in countries with a very high HDI.

When asked on a **scale of 1-5** the extent to which their organisation had recovered, **the average response was 3.**

Looking forward, respondents were asked what their organisation's priority was for the coming year and the word cloud below shows the centrality of patients to their work.

Respondents were also asked what they felt their respective government's priority should be. Responses were varied and included:

> "Investing in the basic conditions in the health system, diagnostics, personnel, conditions, treatment options and getting clinical trials."
> Breast cancer organisation, Europe

> "Two fold - screening and palliative care. we need to detect cancers early, but in a country that has never had a national screening programme in anything there is always the risk that implementing one will first uncover the true burden of cancer."
> Pan cancer organisation, Oceania

> "Ensuring equal and timely access to quality oncology care by addressing disparities in cancer services, strengthening palliative and home care, and implementing a national cancer strategy focused on prevention, early diagnosis, and patient support."
> Pan cancer organisation, Europe

> "Capacity development and development of specialised doctors; to invest in capacity for advanced equipment and medical supplies to eradicate high dependence on foreign medical facilities and capacity."
> Pan cancer organisation, Africa

CONCLUSION

The picture for cancer patient organisations post COVID-19 is mixed. Some of the changes brought on by the pandemic have become permanent, such as greater use of homeworking. Some changes in response to COVID have also enabled organisations to improve the support they offer patients with online and hybrid events helping them to reach more people and offer more resources.

However, this research clearly shows that many cancer patient organisations continue to face significant challenges. For many of those reliant on fundraising, income is either flat or falling and research programmes are still struggling to recover with a concerning number of organisations reporting reductions in what they spend.

Then there are health systems themselves, with 5 years having passed since the pandemic was first declared and health systems were thrown into disarray, many organisations are still reporting that key services required for the diagnosis and treatment of cancer are yet to return to pre-pandemic levels.

The number of people using the support provided by patient organisations continues to increase – while the level of resources available to those organisations have reduced or remained stagnant. What comes through strongly in this report is the determination of patient organisations to continue to support those relying on them, but what it also shows is that those organisations themselves are likewise in need of support.

ABC GlobAlliance

GLOBAL LUNG CANCER COALITION

GLOBAL COLON CANCER ASSOCIATION

IKCC International Kidney Cancer Coalition

IBTA INTERNATIONAL BRAIN TUMOUR ALLIANCE

WORLD OVARIAN CANCER COALITION

LYMPHOMA COALITION

World Bladder Cancer Patient COALITION

WORLD PANCREATIC CANCER COALITION

GLOBAL **CANCER**
COALITIONS NETWORK

Our Organisation

The Global Cancer Coalition Network (GCCN) is an informal, non-legal entity, comprising of patient-driven global cancer coalitions and alliances.

Contact Us

info@globalccn.org

Follow Us