PATIENT EXPERIENCE SURVEY FINDINGS

In January, we launched our first ever multi-national online survey with members, which aimed to gather information on the care experienced by lung cancer patients in different countries.

We had an amazing response, with more than 900 patients completing the survey from 17 member countries: Argentina, Australia, Brazil, Bulgaria, Canada, Czech Republic, Denmark, Ireland, Mexico, the Netherlands, Peru, Portugal, Spain, Sweden, Turkey, the UK and USA.

After analysing the completed surveys, we can now see interesting differences in the care provided in different countries and useful insights for national and global campaigning.

We are now preparing a global briefing document with all the results, as well as national briefings for all the member countries that took part.

Continues on page 2
The GLCC has launched a new online lung cancer screening resource centre to help our members and advocates campaign for national early detection and lung cancer screening programmes.

The resource centre brings together key publications and evidence, case studies and guidance on how screening programmes can work. There are also interviews with international experts on the practicalities of setting up a national programme.

Over time, our aim is to keep adding to the centre, so if you have any suggestions for other resources that could be added, please email glcc@incisivehealth.com

We’d also like to say thank you to Pfizer for their generous funding of this project, and to all the international experts who contributed insights.

Click here to visit the GLCC’s lung cancer screening resource centre.
OUR AMAZING RESPONSE TO COVID-19

We’re proud the GLCC and its members have responded swiftly and intelligently to ensure people affected by lung cancer can access the information and the support they need during this uncertain time. Here are some of the highlights of what we’ve been up to.

The Lung Ambition Alliance, of which the GLCC is a founding partner, compiled an initial list of resources to help people affected by lung cancer navigate COVID-19.

This list features links to lung cancer organisations, including many GLCC members, and a visual summary of topics covered by each organisation.

[Link to find out more]

Roy Castle Lung Cancer Foundation launched a new Keep in Touch support service to help people express their frustrations and cope better during the pandemic.

The service allows a person living with lung cancer to arrange for a member of the charity’s support team to call them each week, fortnight or month, at an agreed time.

This helps to ensure that people have access to the food and medicines they need and gives them the opportunity to ask questions and talk through their concerns.

[Link to find out more]

Lung Cancer Canada has created a series of webinars that focus on a number of COVID-19 and Lung Cancer topics. These include Living with COVID-19 and Lung Cancer and COVID-19: How to Maximize Your Health, Happiness and Immune Function While at Home.

In addition, Lung Cancer Canada has published an audio interview in which Christina Sit, Programs Director at Lung Cancer Canada, asks Dr. Paul Wheatley-Price the most common questions about COVID-19 that people with lung cancer have contacted the charity about.

[Link to find out more]

Irish Cancer Society has extended the operating hours of its Cancer Nurseline to seven days a week, after a significant increase in demand. The service is also now dealing with new queries from patients and carers on unemployment, tenants’ rights, mortgage payments and many other concerns.

In addition, the organisation has developed a new coronavirus and cancer FAQs webpage for patients, and its trained staff so they can provide advice on non-medical coronavirus issues.

New leaflets and posters have also been distributed to people with cancer who are shielding, and the charity has launched a Staying well while staying at home section on its website and a telephone counselling service.

[Link to find out more]

Prevent Cancer Foundation has made two grants of $10,000 to lung imaging researchers at the Mount Sinai School of Medicine in New York.

These funds launched a project to help leverage decades of lung imaging research for use in the detection and management of COVID-19 patients, and particularly those in the early stages of the disease who are symptomatic.

The large worldwide, open source database of anonymised images will be deployed as rapidly as possible to help healthcare providers around the world know how to better manage patients when they first present with symptoms and guide decisions about care, including need for intubation.

[Link to read blog post from the Professor of Radiology leading on the CT imaging project at Mount Sinai School of Medicine.]
Lung Cancer Research Foundation (LCRF) has hosted weekly livestream gatherings to give the lung cancer community a forum to talk with each other, share information, pose questions to medical professionals and lung cancer researchers, discuss the impact of COVID-19 on their mental health, and hear tips on nutrition and self-care.

LCRF also developed an information sheet specifically for patients and caregivers titled COVID-19 and lung cancer, and listed all relevant resources on a COVID-19 webpage.

Like many other organisations, the charity has also created virtual versions of all its community and special events, workshops and patient engagement activities, helping to keep its supporters and their families safe.

CancerCare has created a new coronavirus landing page, which features helpful resources for people affected by cancer and a list of reputable organisations for additional information.

CancerCare has also developed new coronavirus-related fact sheets, including one on telemedicine (the remote delivery of healthcare services). This covers how people can communicate with their healthcare provider through video-conferencing technology, reducing the risk of exposure to the coronavirus.

Lungkreft Foreningen of Norway has developed a number of resources, including a five-minute video from professor and immunologist Anne Spurkeland. In the video Professor Spurkeland presents facts about COVID-19, offers advice and explores the risk for people with lung cancer.

In addition, Lungkreft Foreningen produced a webinar on lung cancer and coronavirus, which is available on its website.

AEACaP (Spanish Association of Lung Cancer Patients) has successfully delivered a range of online webinars to support people during the pandemic.

Topics include the doubts patients may have when visiting medical centres; the effect confinement may have on mental health; and the risks and preventative measures when confinement ends and a new normality begins.

In addition, AEACaP has started to deliver psychological support through online video platforms; and the organisation has published information and guidance for people affected by cancer during this uncertain time.

Longkanker Nederland’s response included publishing the story of a member of its patient panel, Ingrid van Berkel.

She has stage IV lung cancer and was diagnosed with COVID-19 in March. But despite feeling very ill and losing six kilos in two weeks, she did not end up in intensive care and is now completing a special rehabilitation programme, which should take six months.

APOZ of Bulgaria carried out an online study at the beginning of the epidemic that involved nearly 1,800 patients sharing their worries and fears and the complications they face because of COVID-19.

The results of the study have been shared with healthcare providers to help stimulate helpful conversations between people with cancer and members of their care and support team.

APOZ has also shared recommendations from scientific organisations such as WHO, ASCO and ESMO. And in collaboration with the Bulgarian Oncological Scientific Society, it is developing a series of videos which feature recommendations from key multidisciplinary specialists for cancer patients.
WELCOME FORMOSA CANCER FOUNDATION

The first of two organisations to recently join the GLCC is Formosa Cancer Foundation, which was founded in Taiwan in 1997.

Its mission is to reduce cancer incidence and cancer-related death through public education which focuses on cancer prevention and early detection. The organisation also aims to improve access to and raise the quality of cancer care and treatment for the people of Taiwan.

In addition, FCF provides direct services to support the recovery of people with cancer and reduce the risk of recurrence. These include two Survivor Care and Education Centers in Taipei and Kaohsiung, where oncology nurses, dietitians, social workers and psychologists provide tailored supportive care, psychological counselling and nutritional guidance.

FINANCIAL SUPPORT, INCLUDING NUTRITIONAL AND TRANSPORTATION SUBSIDIES AND EMERGENCY FINANCIAL ASSISTANCE, IS ALSO A KEY AREA OF THE ORGANISATION’S WORK.

Please click here for more information.

INTRODUCING CAMPAIGNING FOR CANCER

We’re delighted to welcome South Africa’s Campaigning for Cancer to the GLCC.

It is one of the country’s leading NGOs and focuses on three main areas:

Access to information
Campaigning for Cancer aims to ensure people affected by cancer have access to credible and reliable information about all aspects of cancer, including treatment and patient rights.

Access to support
Campaigning for Cancer helps people affected by cancer access support groups that can provide guidance, advice and emotional support to improve their quality of life, during and after their treatment.

Patient advocacy
Campaigning for Cancer helps people with cancer to access the treatment they are entitled to, regardless of whether they are being treated in a state hospital or belong to a medical scheme. The organisation also lobbies for the promotion and protection of the rights of people affected by cancer and advises patients on how to deal with workplace issues arising from their cancer diagnosis.

Please visit campaign4cancer.co.za for more information.

FCF’S E-CANCER CARE APP

During lockdown, Formosa Cancer Foundation’s e-Cancer Care app has proved increasingly popular with people affected by cancer, including lung cancer patients, survivors and caregivers.

The app allows people to send personal questions to oncology nurses, dietitians, psychologists, social workers and private insurance consultants, which are then answered within 24 hours.

Educational films on nutrition, psychosocial readjustments and exercise are also available through the app, as well lectures from leading clinicians and information on the most up-to-date and innovative treatments for different cancer types.

On top of this, people affected by cancer with money worries can also apply for financial support offered by FCF.

Educational films on nutrition, psychosocial readjustments and exercise are also available through the app, as well lectures from leading clinicians and information on the most up-to-date and innovative treatments for different cancer types.

Please visit campaign4cancer.co.za for more information.
ANSWERING TOP SEARCHED LUNG CANCER QUESTIONS

In May, Lung Foundation Australia launched a first-of-its-kind public health campaign called Lung Cancer Search & Rescue.

This new online initiative seeks to change the narrative on lung cancer by replacing the bleak and often inaccurate answers provided for the 30 most Googled questions on lung cancer. Instead, it offers empathetic, relatable, hopeful and action-orientated content that’s delivered by patients as part of a video series.

To provide this groundbreaking content, Lung Foundation Australia worked with 14 Australians living with lung cancer, who cover a diverse range of top-ranking Google questions on lung cancer.

For example:
Those searching for answers on survival are met by Terri Byrne from Townsville, who has lived with lung cancer for 10 years. As well as delivering honest facts such as lung cancer has a five-year survival rate of just 17% in Australia, Terri also shares personal advice and reasons to be hopeful for the future.

While those searching for answers on the stages of lung cancer are met by Natasha Paul, a young mum who is currently living with stage IV lung cancer. She offers advice on how to navigate the health system at each stage of lung cancer and explains the differences between the different stages.

For more information about the Lung Cancer Search & Rescue service, please click here.

CANCERCARE LAUNCHES PODCAST SERIES

CancerCare, one of the GLCC’s members from the US, launched its Cancer Out Loud: The CancerCare Podcast in March this year.

Cancer Out Loud features conversations with people living with cancer, caregivers, survivors, loved ones and the bereaved. Each episode aims to pull back the curtain on key topics, including living with cancer during the coronavirus pandemic; being part of a support group; maintaining a career during treatment; coping with grief.

“CancerCare is thrilled to be able to launch this podcast,” said CEO Patricia J. Goldsmith. “Each episode shares honest and real conversations with our clients. Their emotional, powerful and important stories are sure to resonate with people impacted by cancer everywhere.”

“This is such an exciting project,” said Sarah Paul, CancerCare’s Social Work Senior Program Director. “Being able to work with clients in creating a narrative that they want to share is incredibly rewarding. This is just the first step of many to allow clients to share their stories in a new and innovative way.”

To find out more about Cancer Out Loud, and to listen to the podcasts, please click here.

ANOTHER STRONG LUNG CANCER VOICE SADLY BECOMES SILENT

On 4 July 2020, Yann Fränckel, a member of Sweden’s Lungcancerföreningen, passed away.

Here, Leif Carlson, Chairman of Lungcancerföreningen, pays tribute to a dedicated and inspiring lung cancer voice:

“Yann was deeply engaged with our organisation, always interested and involved in our work, responsible for our podcast and discussions about all matters regarding lung cancer.

Yann also appeared in the media several times, giving a face to lung cancer patients and was well informed about what was happening in the field of lung cancer research.

Among other things she had a great interest for the work of the Global Lung Cancer Coalition and represented us at their annual meetings and kept us all well informed about what was going on. I’m sure the Coalition benefitted much from her wisdom and her refreshing way of discussing issues.

Her death is a great loss but the good work of Lungcancerföreningen will go on in her honour and memory.”
EXAMINING CROATIA’S SCREENING PROGRAM

After Croatia became the first European country to launch a national lung cancer screening programme, Samo Pitamic from Slovenia’s NAVDIH decided to find out more about this unique initiative.

He conducted an interview with Professor Marko Jakopovic from the Clinical Center for Pulmonary Diseases Jordanovac in Zagreb and discovered the following.

The programme is aiming to reduce mortality by 20–30%
To secure funding, Professor Marko Jakopovic says politicians were told the programme would detect many cases of lung cancer at a very early stage and that, on this basis, lung cancer mortality in Croatia would be reduced by 20–30%.

He adds they also informed politicians the programme would significantly reduce costs associated with treating patients in the late stages of the disease, because surgery is a much cheaper option than systemic treatment with drugs including immunotherapy.

Jakopovic also states the team behind the programme must ensure that it’s completely separate from regular CT examinations, and in no way affects normal diagnostic activities.

Modified version of the I-ELCAP programme
Jakopovic reveals Croatian experts used the I-ELCAP (International Early Lung Cancer Programme) in the US as the starting point for their screening program. This was because I-ELCAP has by far the most experience with CT screening and the lowest percentage of false-positive diagnoses.

Croatian experts than modified I-ELCAP and supplemented it with the dynamic volumetric method of assessing lung nodules, which was used in the breakthrough NELSON clinical study. The program was also modified by automated assessment of lung nodules, due to recent research results.

Personal physician at the center of the programme
To avoid recruitment issues encountered in other countries, Jakopovic says Croatia has put a general practitioner at the center of the programme. They act as an information platform to help identify a person at increased risk.

In addition, the GP monitors the candidate in the screening programme, receives results of the screening examination and records the dates of further examinations.

Left to right: Samo Pitamic and Professor Marko Jakopovic

The programme promises many parallel benefits
Jakopovic says they expect the programme to result in many parallel benefits, based on the results of the I-ELCAP program. These include smoking cessation and the detection of illnesses such as emphysema or interstitial lung disease and other pathological changes in the chest and liver.

However, Jakopovic points out that these parallel activities will not “burden” the lung cancer screening programme, and the basic goal remains the rapid diagnosis of lung cancer and immediate action.

Croatia is set up to deliver an effective programme
Jakopovic says the programme has 16 low-dose CT machines at its disposal. He believes this is sufficient to deliver an effective programme, given that there are an estimated 50,000 to 100,000 smokers in Croatia with an increased risk of lung cancer.

However, he also says that the programme’s success will depend on the responsiveness of the smoking population and the participation of doctors at the primary level.
IASLC’S COVID-19 RESOURCE

The IASLC has developed a guide to COVID-19 and lung cancer that’s available on its website.

It features member and patient experiences of COVID-19, information from the Journal of Thoracic Oncology, and official statements from the IASLC.

In addition, the guide features links to important resources such as journal articles and social media groups relevant to the care of patients with lung cancer.

If you would like to share a video or written statement about your personal interactions, concerns, guidance and hopes, you can email a submission to COVID19@iaslc.org

Please click here for more information.

WORLD FIRST ROBOTIC LUNG AND THROAT CANCER DOUBLE OP

In March this year, Guy’s and St Thomas’ in London revealed it had carried out the world’s first robotic surgery to remove throat and lung cancers at the same time.

Performed in August 2019, the operation involved the use of a Da Vinci Xi robot to perform minimally invasive surgery on a father of four. This was to significantly speed up his recovery time so he could begin the next stage of his treatment as quickly as possible, giving him the best chance of cure.

Please click here for more information.

KEYHOLE LUNG CANCER SURGERY

A team at Royal Papworth Hospital in the UK has become the first in the world to remove an entire lung using a pioneering technique.

The non-intubated subxiphoid pneumonectomy was performed in November 2019 to treat a patient with advanced stage 3B lung cancer.

During the three-hour operation, surgical teams made an incision between the abdominal muscles (subxiphoid) to remove the entire lung through a small cut of approximately five centimetres.

Meanwhile, the anaesthetic team controlled the pain through a non-intubated method, meaning the operation was tubeless and the patient kept spontaneously breathing on a gaseous mixture of oxygen, air and sevoflurane, free of opioids.

Please click here for more information.

ONCOLOGY SOCIETIES PUBLISH PANDEMIC GUIDELINES

The Lancet has provided an overview of the cancer guidelines published by oncology societies and national authorities during the coronavirus pandemic.

Organisations featured include the European Society of Medical Oncology (ESMO), Society of Surgical Oncology, American Society of Clinical Oncology (ASCO) and the UK National Institute for Health and Care Excellence (NICE).

Please click here for more information.
LUNG CANCER MEDIA ROUND-UP

LUNG CANCER EUROPE PUBLISHES DISPARITIES REPORT

To mark World Cancer Day in February, Lung Cancer Europe (LuCE) released a report that highlights disparities and challenges in accessing lung cancer diagnostics and treatment across Europe.

Key findings include:

• 42% of European patients with lung cancer wait more than two months from their first medical consultation to receiving their diagnosis.

• There are differences between Western/Northern and Eastern Europe on access to molecular testing. Patients from Croatia, Romania, Poland, Latvia, Turkey and Spain do not have access to three or more molecular tests.

• In Eastern Europe, most drugs are not reimbursed or are only available at full cost to patients.

Please click here for more information and to download the report.

LUNG CANCER IN NON-SMOKERS BIOLOGICALLY DISTINCT

Lung cancer in non-smokers is a biologically distinct disease from that in smokers, new research suggests.

Scientists at the Institute of Cancer Research (ICR) in London say that many people who had the disease but did not smoke showed signs of DNA damage from cancer-causing substances that are present in the environment, such as vehicle exhaust fumes. These genetic changes were found to vary depending on a patient’s age or sex.

The researchers believe the findings could pave the way for tailored treatments based on newly identified genetic changes.

Please click here for more information.

SCLC FIRST-LINE TREATMENT APPROVED BY FDA

In March, America’s Food and Drug Administration (FDA) approved Imfinzi (durvalumab) in combination with etoposide and either carboplatin or cisplatin as first line treatment of people with extensive-stage small cell lung cancer.

The FDA based their approval on the results of the clinical trial CASPIAN, which showed patients receiving Imfinzi in combination with chemotherapy lived longer and had more time without disease progression; while a higher percentage of patients responded to this combination treatment than those on chemotherapy alone.

Imfinzi is only the second immunotherapy drug to be approved by the FDA for first line treatment of small cell lung cancer.

Please click here for more information.

MENTAL HEALTH AND LUNG CANCER STUDY

A new study suggests one-third of patients newly diagnosed with non-small cell lung cancer have moderate to severe symptoms of depression.

Barbara Andersen, lead author of the study and professor of psychology at Ohio State University, said the results suggest doctors need to screen patients for depression and then refer them to appropriate care, when necessary.

Please click here for more information.
In our ongoing series of How to... features, we provide some of the best ideas on how to fundraise virtually.

Because of the coronavirus pandemic, we know most of our members have found it almost impossible to continue with their normal fundraising activities and events.

To help you during this difficult time, we’ve listed some great virtual fundraising ideas below and provided top tips on how to make these fundraisers a success.

**Virtual sporting events**
GLCC members may traditionally organise sponsored marathons, fun runs and bike rides to raise money. To replace these community events, you could encourage supporters to do the same activity but at any time they want, and even across a number of days.

What’s particularly crucial to the success of these events is getting participants to post photos or videos of themselves completing their challenge to social media, tagging your organisation’s account and using a hashtag that’s simple, authentic and catchy.

**Gaming fundraisers**
Video games are a great fundraising idea right now because can bring people together around a common interest whilst they remain in their own homes. The versatility of video games also means you can create something as simple or complex as you want to generate income.

For example, you could organise:
- a 24-hour or week-long gaming marathon
- a tournament for a specific game with a prize
- a challenge to see who completes a game in the fastest time.

In addition to video games, you could also try something more traditional that brings people together in their own homes and virtually. This includes:
- a quiz night that involves participants using a quiz app on their phones
- a board game evening or marathon.
Online competitions
Another option that could help the money come in is an online competition that encourages adults and children to get creative to win a prize.

The art or craft you choose could be anything from painting to pottery, writing to creating a Lego sculpture. Just try to think of something that will connect with and inspire your audience, because people are actively looking for things to do while they spend much more time at home.

As we mention in our top tips below, social media, videos and live streaming can be vital to the success of virtual fundraisers, and especially an online competition. So do remember to encourage people to share their entries online, and don’t forget to promote them yourself through your organisation’s channels.

Streaming virtual events
The coronavirus pandemic has seen many things move into the streaming space, from live cook-alongs to gym classes. To raise money, you could encourage people to give a donation to attend one of these virtual events or a series of them.

In addition, you could approach individuals (such as a celebrity supporter) or organisations (such as theatres or music venues) and ask them if they’d be willing to support your charity. If they’re happy to do this, they could stream a live performance or make available a recording of a show they own the rights to. They could then ask the public to give a donation to your organisation to watch this exclusive virtual event.

Online auctions and raffles
Popular fundraisers such as auctions and raffles can easily be moved online with the use of specialist software. And what’s particularly great about this type of fundraiser is that people of all ages are familiar with them, which helps to increase involvement.

In addition, virtual auctions and raffles can often be much cheaper to run than the real thing, because you don’t have to pay for printed materials, venues and other associated costs.

TOP TIPS ON HOW TO FUNDRAISE VIRTUALLY

1. **Create a clear vision** and purpose for your event, ie make sure people understand why they should get involved.

2. **Tell personal stories** that help to bring to life why people should get involved in your virtual fundraiser. You could also highlight how people have took part in a virtual fundraiser in the past.

3. **Aim for a fundraising target**, or ask participants to state a target amount on their online fundraising pages. This tends to increase income.

4. **Promote your event on social media**, and ask participants to do the same. This can be vital to creating a successful event.

5. **Don’t forget to email supporters** who may not be on social media. During the pandemic, people of all ages are looking for distractions and something to do that has a positive effect on the world.

6. **Use videos or live streams** to help tell your story and why the event is so important.

7. **Keep supporters updated** about the progress of an event, for example, how many people have signed up for it and the amount of money raised so far.

8. **Keep talking about your event after it’s ended**, and encourage participants to do the same. That’s because many people donate retrospectively.

9. **Track and record data**, including how many people took part, how much they raised and their contact information.

10. **Follow up with a short survey** that asks people what worked in your fundraiser and what didn’t. Also, thank them for their participation.
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