

UNITY



The newsletter of the Global Lung Cancer Coalition

Winter 20 | Spring 21

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WELCOME

In 2001, nine organisations with an interest in lung cancer came together and formed the Global Lung Cancer Coalition.

Today, 20 years later, the GLCC is comprised of 41 non-government patient organisations from around the world.

Our aim is to increase awareness of lung cancer issues, change perceptions of lung cancer, help people with lung cancer access the information and support they need, and push governments and legislative bodies to improve treatment and care.

Already, we have achieved a lot. But we also know that much more must be done to improve the outcomes and lives of people affected by lung cancer – something we are determined to do.



To join us, please read our membership criteria, and download a membership application form at lungcancercoalition.org

SCREENING RESOURCE CENTRE UPDATE



The GLCC has added new materials on how screening protocols were adapted to protect staff and participants during the COVID-19 pandemic to its lung cancer screening resource centre.

We also recently concluded a global literature search for publications and will make further additions in the coming weeks.

In addition, we'd like to hear from any member that's identified new publications in their country which they think the centre should feature, including journal articles, policy documents, clinical guidance or patient materials.

Any contribution you make will help to strengthen the centre as the place

to go to for up-to-date evidence about lung cancer screening and clinical guidance, and best practice to support national implementation.

We are also proud to report that the GLCC gave a short video presentation about the resource centre at the IASLC World Conference on Lung Cancer, which was held remotely in January.



Please click here to visit the GLCC's lung cancer screening resource centre.



GOOGLE TRANSLATE

Articles marked Google Translate have been translated from a non-English news story. This means you may need to paste the story into Google Translate and select your appropriate language.

MEASURING THE IMPACT OF LUNG CANCER RESEARCH

The GLCC's latest paper into worldwide lung cancer research was published in the journal *Lung Cancer* in February 2021 and focuses on how best to measure the impact of medical research.

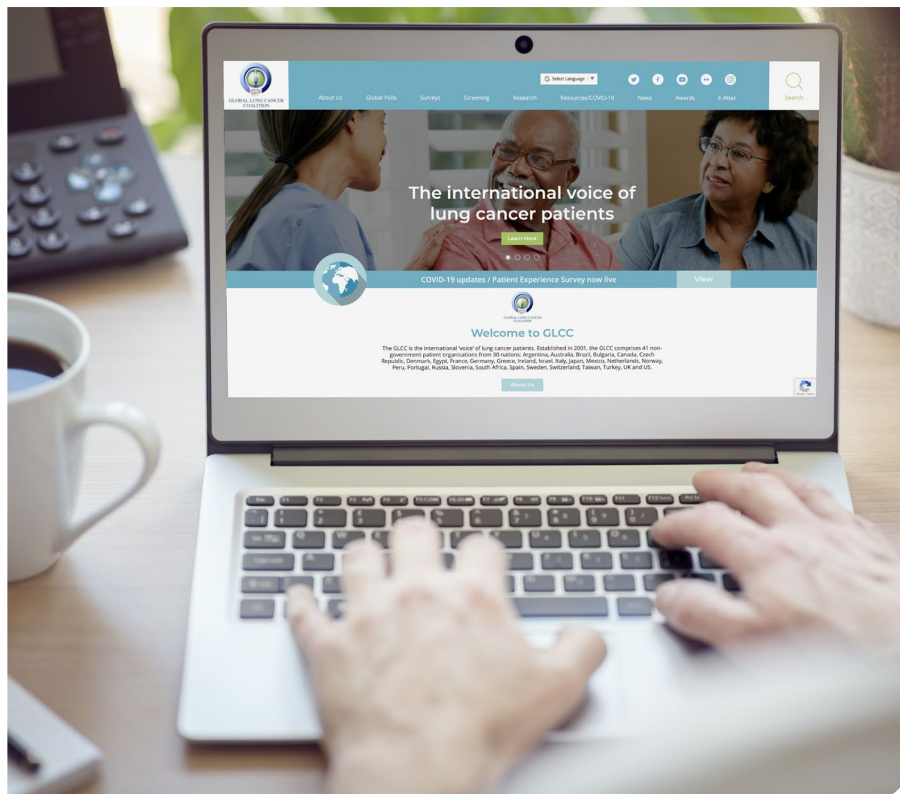
Traditionally, the impact of medical research is judged by how many times it is cited in medical literature. But our new paper argues a potentially better evaluation of lung cancer research is an assessment of how much it contributes to clinical practice guidelines on how to prevent, diagnose and treat illness.

The researchers involved in the study drew this conclusion after comparing 7,357 references in 77 lung cancer clinical practice guidelines with 73,214 lung cancer papers published on the Web of Science between 2004 and 2018.



Please click here to read more about the study.

WE HAVE A NEW WEBSITE!



The GLCC is delighted to report that we have a new website that aims to make it easier for members to access our research data and wide range of resources.

We took the step to create a new site because over the past five years we've added a lot of content to our old site that's not available in the most logical or intuitive place.

As well as making the new website simpler and much easier to navigate around, we've given the site's appearance a refresh too without moving far away from the core look of the old site.

If you do have any views about the new GLCC website, positive or negative, we'd love to hear from you.



Please drop us a line at glcc@roycastle.org

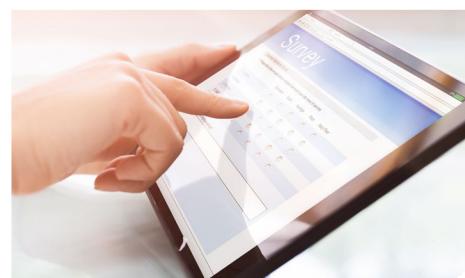
SECOND PATIENT EXPERIENCE SURVEY

Thank you to all the GLCC members who circulated our second patient experience survey to the people they work with and support.

Our aim now is to analyse the hundreds of responses we received and submit our findings for the next World Conference on Lung Cancer in September 2021.

We're especially interested to find out how the pandemic has affected patients physically and emotionally, and whether it has led to any changes in how they contact their medical team.

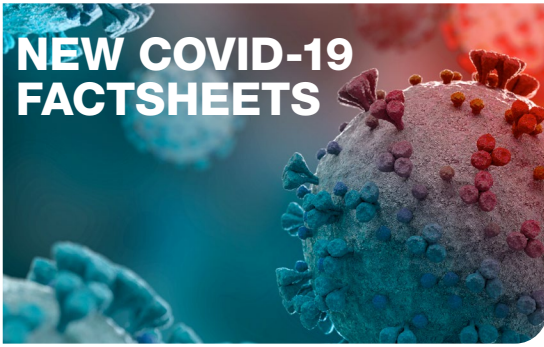
For example, have people been having telephone or video consultations with their healthcare team rather than meeting a professional face-to-face?



The findings from our second patient survey will be posted on our website, when available. You can view the results from our first survey by clicking here.



NEW COVID-19 FACTSHEETS



The GLCC has developed new factsheets on lung cancer and COVID-19 and the differences between the symptoms of lung cancer and COVID-19.

These two factsheets, along with our others on immunotherapy, lung cancer screening, smoking cessation, and clinical trials, are available to download in 17 languages.



Click here to visit the factsheets section of the GLCC website.

IRISH CANCER SOCIETY'S COUGH CAMPAIGN

Following a significant decline in referrals to lung cancer services because of COVID-19, the Irish Cancer Society launched its 'Your cough could be masking something else' campaign in September 2020.

The success of the campaign was measured in media coverage, social media and online interactions, and e-referral numbers.



Click here for more information.



50 separate pieces of media coverage, with a total reach of over 22.5 million people.



Over 600,000 Facebook impressions and almost 250,000 Twitter impressions.



Over 5,000 views of The Irish Cancer Society's lung cancer webpages.



A 29.3% increase in e-referrals to rapid access lung clinics, from 109 referrals in August to 141 in September.

LUNG AMBITION ALLIANCE AND WEF PUBLISH COVID-19 REPORT

In January 2021, the Lung Ambition Alliance and World Economic Forum published a new report titled 'Learning lessons from across Europe: Prioritizing lung cancer after COVID-19'.

This report was developed to share lessons learned in European countries during the peak of the pandemic, and to provide recommendations to address the short-term impact to lung cancer care and develop long-term system resiliency.

The LAA and WEF state in the report that there is an opportunity to emerge from the crisis in a better position to improve diagnosis, treatment and care to reduce lung cancer deaths in the future.



Please click here to find out more about the report and to download it.



NEW PARTNERS FOR THE LUNG AMBITION ALLIANCE

The Lung Ambition Alliance, of which the GLCC is a founding member, welcomed five new project partners in October: Bristol Myers Squibb, Eli Lilly and Company, Genentech, Merck and Novartis.

The aim of the Alliance is to double five-year survival for patients with lung cancer by 2025 through three pillars: increasing screening and early diagnosis, delivering innovative medicine, and improving the quality of care for people with lung cancer.

Two projects that are being accelerated through the LAA's work with the five new partners are:

The Major Pathologic Response Project – the assessment of clinical trial data and research to validate surrogate endpoints and identify predictive biomarkers, which may enable better targeting of tumour characteristics.

COVID-19 and lung cancer junior faculty grants – the LAA and its project partners made grants available for groundbreaking research that aims to provide a better understanding of how COVID-19 affects patients with lung cancer.



Please click here to find out more.

NEW US STUDY SEEKS ORIGINS OF YOUNG LUNG CANCER

GO2 Foundation for Lung Cancer and Addario Lung Cancer Medical Institute (ALCMI) in the US have launched a study to gain a better understanding of the underlying causes of lung cancer diagnosed in people aged under 40.

The Epidemiology of Young Lung Cancer study seeks to identify possible clues from environmental and childhood exposures and other risk factors that help to prevent, diagnose early and more effectively treat lung cancer in young patients.

This work builds on ALCMI's Genomics of Young Lung Cancer study, which took place between 2014 and 2017 and found that 84% of participants with lung adenocarcinoma had specific mutations potentially treatable with targeted therapies or precision medicine.



Click here for more information.

DANGERS OF VAPING STUDY PUBLISHED IN AUSTRALIA

Lung Foundation Australia has urged parliamentarians in Australia to urgently address the rise in the use of unregulated flavoured e-cigarettes among the country's youth.

This call comes after Lung Foundation Australia and the Minderoo Foundation published a report in December 2020 on the composition and toxicity of 52 e-liquids supplied or manufactured in Australia. It found that:

- 100% of e-liquids had between 1 to 18 chemicals which have unknown effects on respiratory health.
- None of the brands had a complete accurate ingredient list, which would be noncompliant with European Union labelling regulations.
- 21% of e-liquids contained nicotine or nicotine (despite it being illegal to sell e-liquids containing nicotine in all Australian states and territories).
- 62% of new e-liquids and 65% of vaped e-liquids contained chemicals likely to be toxic if vaped repeatedly.



Click here to find out more.

PROVIDING HOLISTIC SUPPORT IN ISRAEL

The Israeli Lung Cancer Foundation has launched a new area on its website called the Compound, which aims to help people live well with lung cancer.

The different sections of the Compound focus on:

Movement therapy – featuring exercise tips and a video from a physiotherapist.

Good nutrition – advice from a clinical dietitian and recipes to help prevent weight loss.

Mental health care – an oncology psychiatrist provides tips on how to manage anxiety and other mental health issues.

Mobilising family and friends – advice on how to use the skills and experiences of loved ones to support a patient through their lung cancer journey.

Rediscovering yourself – stories from lung cancer patients about how they have chosen to live and thrive following their diagnosis.

Getting through a difficult time – advice on how to build resilience within a family unit when a member is diagnosed with lung cancer.



Click here for more information.
Google Translate



Following the efforts of the Canadian Lung Association and other health organisations, the government in Canada has announced new draft regulations to limit the maximum nicotine concentration in vaping products.

Prior to these regulations the maximum nicotine concentration in Canada was three times that of other jurisdictions, for example, the European Union, where a maximum of 20mg/ml is in place.



Click here for more information.



NEW REPORT ON LUNG CANCER STIGMA

A report on stigma and lung cancer co-authored by Maureen Rigney and Jennifer King of GO2 Foundation for Lung Cancer was published in the *Journal of Thoracic Oncology* last October.

Titled 'A 10-year cross-sectional analysis of public, oncologist and patient attitudes about lung cancer and associated stigma', the study involved participants completing the same survey in 2008 and 2018 and researchers using the same methodology to analyse the answers provided.

The key findings from the study included:

- Participants felt there had been improvements in treatment over the decade, including the availability of more treatment options.
- The public had a greater knowledge of lung cancer in 2018 than in 2008.
- There was no significant change in the percentage of the public reporting that patients with lung cancer are at least partially to blame for their illness – 59% in 2008 versus 60.3% in 2018.



Maureen Rigney of GO2 Foundation

- In 2018, more people with lung cancer agreed there is a stigma associated with lung cancer – 72.1% versus 54.5%.
- More people with lung cancer in 2018 (69.4% versus 50.8%) said those diagnosed are viewed or treated differently by society in general.



Click here for more information.



See page 10 for an interview with Maureen Rigney and Jennifer King about the report.

CAROLYN ALDIGÉ ENCOURAGES SCREENING IN WALL STREET JOURNAL

Carolyn Aldigé, Founder and CEO of Prevent Cancer Foundation, had a letter titled 'Now isn't the time to let up on cancer screening' published as the lead letter in the *Wall Street Journal* on 21 January 2021.

In the letter, Carolyn encourages Americans to keep routine cancer screening appointments or reschedule the ones they have missed, as they can dramatically improve patient outcomes.

This is because research conducted by the Prevent Cancer Foundation has revealed a significant portion of US adults have missed or postponed scheduled cancer screenings during the pandemic, and African-American and Hispanic people have been disproportionately affected.

LUNG CANCER AND EQUITY OF CARE IN CANADA

Lung Cancer Canada published a new report titled *Lung cancer and equity: A focus on income and geography in November 2020*.

It focuses on the social determinants of health and their impact on lung cancer risk, access to care and outcomes for people with low income and people who live in rural and remote communities.

The report also outlines the policy and system-level changes needed to reduce inequities and provide better care for everyone living in Canada.



Click here to read the report in full.



Click here to listen to a podcast about the report.

YASSOU, FAIRLIFE!

We'd like to say a big hello to FairLife Lung Cancer Care of Greece, which has become the 41st member of the GLCC.

FairLife is the first non-profit organisation in Greece dedicated to reducing deaths from lung cancer and improving the lives of people affected by the illness.

It was established by Korina Pateli-Bell in memory of her husband, Simon Bell, who was lost to lung cancer in August 2020.

We very much look forward to working with and supporting FairLife Lung Cancer Care in the future.



FairLife Lung Cancer Care was set up in memory of Simon Bell.



Click here to find out more.



YOUR LUNG CANCER AWARENESS MONTH

Last November, despite the impact of COVID-19, GLCC members launched fantastic events and activities to spread the word about the biggest cancer killer.



Canada

Lung Cancer Canada hosted its 10th annual Evening of Hope, but this time people attended the celebratory event via their computer screen.

On the night, a number of speakers delivered talks, people with lung cancer told their personal stories and lots of great prizes were up for grabs in a virtual raffle.



Spain

AEACaP launched a new edition of its #DameTuAire (Give me your air) campaign on social media to increase awareness of lung cancer issues throughout November.

This involved AEACaP focusing on the quality of life of patients and their families in the first week of the campaign; the prevention of lung cancer in the second week; the importance of early diagnosis in the third week; and the need to invest in lung cancer research in the final week of the campaign.



Italy

Alcase Italia held its sixth Illumina Novembre campaign to raise awareness of lung cancer and issues that surround the illness.

This involved people attaching white lights, ribbons, bows and balloons to private houses, public buildings and monuments in an estimated 100 towns and cities across Italy.



UK

Roy Castle Lung Cancer Foundation launched its Lung Cancer Awareness Month activity in September 2020 rather than the usual month of November.

This was because of the impact of COVID-19 on the entire lung cancer care pathway in the UK, including a 75% drop in urgent referrals to a lung cancer specialist during the first lockdown (March to May).

At the heart of the Foundation's activity was a campaign called Still Here. It aimed to make clear that:

- a cough is not always related to COVID-19
- the UK's National Health Service is still here for everyone who needs it, including people with concerns about signs and symptoms that might indicate lung cancer
- the charity is still here to help support and inform all those affected by lung cancer.



Portugal

Pulmonale launched an awareness campaign that focused on improving people's awareness of lung cancer symptoms to increase early diagnoses and save lives.

As part of the campaign, Portuguese actor and comedian Eduardo Madeira featured in a social media video to help spread this important message.



US

GO2 Foundation for Lung Cancer launched a campaign called It's Personal, which asked the lung cancer community to help spread awareness and take action.

Through its Lung Cancer Awareness Month webpage, the charity provided handy communication tools and guidance on how to use fact graphics, selfie videos and other resources to promote the campaign.



Europe

WALCE took part in a range of activities to support people with lung cancer and inform adults and children about the dangers of smoking and the symptoms of lung cancer.

LUNG CANCER MEDIA ROUND-UP

SUCCESS AT IDENTIFYING EARLY-STAGE LUNG CANCER IN TAIWAN

TALENT, a national lung cancer screening study conducted in Taiwan, has confirmed that low-dose CT screening may be feasible in a predefined, never-smoking, high-risk population. The study uncovered lung cancer in 2.6% of the 12,011 individuals screened, exceeding the 1.1% and 0.9% lung cancer detection rates documented in the US National Lung Screening Trial and the NELSON trial.



[Click here for more information.](#)

TARGETED THERAPY REDUCING LUNG CANCER DEATHS IN THE US

New data from the US National Cancer Institute (NCI) which focuses on lung cancer incidence and mortality between 2006 and 2016 has shown clear signs that targeted therapy is helping to prevent lung cancer deaths. Analysis revealed that deaths from non-small cell lung cancer among US men began to fall much more sharply when targeted therapies started to be used from 2013.



[Click here for more information.](#)

EUROPEAN CANCER ORGANISATION REPORT PROVIDES ROADMAP TO HIGH-QUALITY CARE

In December 2020, the European Cancer Organisation launched an action report titled 'Leave no one behind – Delivering innovation in lung cancer care'. It aims to provide organisational specifications, not clinical guidelines, and is intended to give oncology teams, patients, policymakers and managers an overview of the elements needed in any healthcare system to provide high-quality multidisciplinary care throughout the patient journey.



[Click here for more information.](#)

DRAMATIC DROP IN CANCER DRUG TRIALS

Data from the Medidata Enterprise Data Store has shown that there was a 60% decrease in new clinical trials for cancer drugs and biological therapies during the COVID-19 pandemic. During a 40-month observation period, 1,440 phase 1–4 oncology trials were launched in 91 countries; of these trials, 1,249 were started in the period before the pandemic, but just 191 since COVID-19 hit.



[Click here for more information.](#)

CANCER GUIDELINES IN US FAILING AFRICAN-AMERICANS



Despite findings that African-American people in the US are more likely to die of lung cancer than white Americans, new findings published in the Journal of Thoracic Oncology suggest that current screening guidelines fail to properly consider the patterns of smoking and lung cancer in this population.



[Please click here for more information.](#)

ONLINE CONSULTATION TOOLKIT FOR MEDICAL PRACTITIONERS

The National Health Service in England published a new resource in January 2021 called 'Using online consultations in primary care: implementation toolkit'. It's an interactive document that provides a range of ideas and options for different professionals, including clinicians, at different points in their implementation journey.



[Please click here for more information.](#)

ROLE OF LUNG CANCER NURSE SPECIALIST PUBLISHED IN TEXTBOOK

A new article on the role of the lung cancer nurse specialist has been published in the 2020 edition of the Reference Module in Biomedical Sciences in the UK. The article explains how access to this type of nurse can improve the patient experience and outcomes for people with lung cancer.



[Please click here for more information.](#)

HOW TO... RUN AN EFFECTIVE VIRTUAL MEETING

In our ongoing series of How to... features, we provide some top tips on how to host productive meetings with people situated in different locations.



1. Choose the right platform

There are many different platforms you can choose to host a virtual meeting on. So when you start to plan a meeting, take time to review each one carefully before you decide which platform best suits your needs.

Also consider whether it's worth downloading free apps or paying for extra features that could enhance your meeting. These include:

live polling – create questions with predefined answers to get fast responses and keep your audience engaged.

online whiteboard – perfect for brainstorming and collaboration in real time and learning sessions.

screen sharing – most platforms allow you to share with a small number of people, but there are some apps that allow you to share with thousands.

sticky notes – create different boards and allow people attending your meeting to drag and pin notes to these boards.

breakout rooms – assign people to private rooms so they can work together and then bring them back to the main meeting.



2. Develop your hosting skills

The success of a virtual meeting is often dependent on the person who is hosting it. This means it's important to develop skills and knowledge that will help you feel confident and make you proficient in this role. These include:

understand the software you're using – it's often worth hosting a quick rehearsal meeting on your chosen platform and trying out any tools and apps you're not familiar.

learn how to use ice breakers – helping participants to feel relaxed and getting them acquainted with each other can be key to the success of a meeting.

know how to keep energy and momentum high – think about learning some activities or games that can boost energy and keep people focused throughout your meeting.

learn how to be a good summariser – telling people succinctly what has been decided, what they have achieved or what's next in the agenda can be vital to keeping people engaged during a meeting.

know how to intervene effectively – sometimes you may need to intervene to keep people focused on an issue, stick to a meeting's schedule or prevent an issue from escalating. Search online for some top tips on how to do this.

record and action – remember a meeting will only be successful if the people who attended it know what the outputs of it are and what the next steps should be.



3. Take time to prepare

Whether you're hosting a face-to-face meeting or a virtual meeting, it's important to plan and prepare for it so it's as successful as possible.

To help you do this, it may be worth considering the following questions and answering them:

What is the objective/s of the meeting?

Who should attend to achieve the objective/s?

What do we need to discuss to achieve the objective/s?

Other considerations

Create an agenda – if you think it will help, create an agenda for your meeting and circulate it several days before your event; also send the URL and login details for the meeting and a list of attendees.

Leave tech to someone else – if you think technology issues may arise during a meeting, it may be worth asking another person to look after the tech so you can focus solely on guiding the discussion.



4. Set ground rules

Establishing and sharing ground rules before and at the start of a meeting can help to ensure a virtual meeting is a success.

These rules may include:

Participants must log in to the meeting five minutes early so everyone can connect and check their audio and video.

Attendees must mute their lines until they are ready to speak to prevent distracting background noise and reduce people talking over each other.

People must state their names before they speak if the meeting is audio only. This will help attendees follow who's said what.

Participants must mute their phone and inbox to ensure the meeting is not disrupted by calls or alarms notifying an attendee they have just received a new email.

No eating during a meeting, as the sound of someone tucking into their lunch or a snack can be greatly amplified on a phone or video call.



5. Remember you're in a virtual world

In virtual meetings, it may be hard for participants to pick up on your facial expressions, tone of voice and body language. As a result, your audience may struggle to understand what you're telling them or want them to do. To prevent this from happening, it can be helpful to do the following:

Put your entire focus on the person who is speaking – demonstrate you've paid attention by summarising what they have said or by asking a relevant question.

Communicate how you feel through your choice of words – an example of this would be, "Jose, I'm really excited that our numbers are so high, but I'm worried about the drop in new clients. How do you feel about this?"

Guide the discussion at all times – for instance, at the beginning of a meeting, don't leave it open to who should introduce themselves first. Instead, identify who you'd like to go first, second, third, etc.



6. Try to get everyone involved

A big challenge with virtual meetings is that often some participants find it hard to get involved and contribute. To prevent this from happening, consider the following:

Regularly pause and use a round robin technique that asks everyone to comment on the subject matter.

Use activities, games and questions that require participation. These don't have to focus on the objective of the meeting. They're more about increasing people's confidence to speak up and get involved.

Identify features and apps that easily allow people to get involved virtually. These include live voting, questions with multiple answers, whiteboards, sticky notes and breakout rooms.



LET'S TALK MAUREEN RIGNEY AND JENNIFER KING

In October 2020, Maureen Rigney and Jennifer King PhD of GO2 Foundation for Lung Cancer published a report on attitudes about lung cancer and associated stigma.

Here, Maureen, the Director of Support Initiatives at the Foundation, and Jennifer, the charity's Chief Scientific Officer, discuss how the study came about and its findings.

Can you tell me briefly about your roles at GO2 Foundation?

Maureen: I've been with the organisation for 15 years and I'm involved in a lot of interesting projects across a wide range of teams, including the study on stigma and lung cancer.

But predominantly my work focuses on ensuring that people diagnosed with lung cancer have access to the patient support and education resources they need.

Jennifer: I oversee GO2's research portfolio. This involves communicating all the research that is happening and making sure scientific information gets out to our patients and caregivers in a digestible way.

A lot of our studies are collaborations, both in-house and with other investigators, so I also work with a wide range of teams. These could be academics or people who also work in the field of lung cancer.

GO2 Foundation first did a study into lung cancer and associated stigma in 2008. How did that come about?

Maureen: At the charity, we knew stigma was an issue. It was very much something we were aware of but hadn't tackled. But it was actually AstraZeneca who came to us and asked if we wanted to do a study into this area.

Having AstraZeneca on board really helped, because we had a much smaller team in 2008. But because of a lack of resources and capacity, it still took until 2014 before the results of the study were published in the Journal of Multidisciplinary Healthcare. However, what we'd identified did inform other areas of our work a lot earlier.

How were the results of the 2008 study used by the charity?

Jennifer: After the charity had identified how big an issue stigma was in the community, it went out and did the 'No one deserves to die' campaign in 2012, which was really provocative.

It shows people saying they deserved to die if they have lung cancer. It really challenged the way people think about lung cancer and challenged their perceptions of these people.

Personally, this campaign was something that attracted me to the organisation as a place to work. The fact that it could take some fairly conservative research and then go to a place that would change the conversation about lung cancer and make a difference to people's lives. That was really fascinating and empowering to me.

Maureen: The original research also led to the creation of a booklet for people diagnosed with lung cancer. We did a smaller research study with some of our volunteers and used that to create an educational piece for folks who are experiencing stigma.

Were there any surprising results from the 2008 study?

Maureen: I wouldn't say there were any surprising results. But we were disappointed that the results pointed to 60% of the general public feeling that people with lung cancer were partially to blame for their illness. So stigma rates were high among the general population, which was not shocking but disappointing.

Were there any expectations about what we might find from the 2018 study?

Jennifer: Lung cancer looked very different in 2018 compared to 2008. It was much more talked about. And because much more lung cancer research was being conducted, it was resulting in new drugs, new therapies and better outcomes in general compared to a decade earlier.

So we'd seen this major shift, but was the way people feel and relate to lung cancer changing? To be honest, I thought that we'd see some improvement. We might see a little bit of change in public perception. But the answer at the end of the day was that public perception had not improved and patients were perceiving and reporting a lot more stigma than in 2008.

Your initial response to this is, "How can this be?" Treatments are better. People are talking about it more. Lung cancer is much more in the news. But when we really thought about it and analysed the lung cancer community, what we identified is that a decade ago people didn't really identify what stigma was. They didn't talk about experiencing it with their neighbour or their clinician and feel it was okay to report this bad feeling.

So the big takeaway from the study is 100% that stigma is still a serious problem. But it's also good to remember that the patient community is more empowered now to report the problem. We have a lot more people who will say I had an encounter with a person who blamed me for my illness.

What are the next steps following the publication of the 2018 study?

Jennifer: We're very much going to keep talking about the problem of stigma at all levels and keep people thinking about all the ways we can attack this issue together. This will include us showing all the different faces of lung cancer and keeping the theme of 'No one deserves to die' out there without explicitly saying those words.

Maureen: Through our work with volunteers about stigmatising experiences, what was identified is that lung cancer survivors find the endless discussion of smoking habits really difficult. When they see medical professionals,

people who have never smoked and people who ended smoking years ago are still asked about their smoking history.

So we've worked with researchers to develop communication training for medical professionals to help them tackle smoking behaviours more sensitively and not stigmatise lung cancer survivors. That's something we'll be rolling out in the future.

Do you have any plans to repeat the study on stigma in the future?

Jennifer: I think it could be worth repeating the study every five or 10 years. Because the snapshot we got this time was really telling in ways we weren't expecting and it was a wake-up call that stigma is still a major problem.

Maureen: I think it would also be fascinating if studies similar to ours were repeated in other countries. Because different countries are in different places in terms of their efforts and awareness. For example, a GLCC survey a few years ago showed that in some countries, where smoking is more normalised, the stigma around lung cancer was lower.

Would you be happy to help other GLCC organisations conduct similar studies in their countries?

Maureen: Of course. We've learnt a lot through our studies and this is something we can pass on to other organisations. And the good thing is that in smaller countries you wouldn't need a sample size of over 1,000. It could be quite a bit smaller.

Conclusions of the report on lung cancer and stigma

- Despite a decade of significant research progress in lung cancer, stigma and blame remain major problems.
- Lung cancer patients are perceiving higher levels of stigma than a decade ago.
- Stigma surrounding lung cancer remains a critical problem, even in healthcare settings.
- We all need to work collaboratively as a community to reduce stigma and support patients with lung cancer.



To read Maureen and Jennifer's full report, which is titled 'A 10-year cross-sectional analysis of public, oncologist and patient attitudes about lung cancer and associated stigma', [please click here](#).

The main statistical findings from the study are on [page 5](#) of this edition of Unity.



Fundación Pacientes de Cáncer de Pulmón: www.fundacionpcp.org



LungFoundation Australia:
www.lungfoundation.com.au



Oncoguia Institute: www.oncoguia.org.br



Bulgarian Anti-Cancer Patient Association (APOZ): www.oncobg.info



Canadian Lung Association:
www.lung.ca

Lung Cancer Canada:
www.lungcancercanada.ca



OnkoMaják
www.onkomajak.cz



Patientforeningen Lungekreft:
www.lungekreft.dk



CanSurvive: www.facebook.com/CanSurvive



La Ligue Contre le Cancer:
www.ligue-cancer.net



Deutsche Krebsgesellschaft E.V:
www.krebsgesellschaft.de



FairLife Lung Cancer Care
fairlifelcc.com



Irish Cancer Society: www.cancer.ie



The Israeli Lung Cancer Foundation:
www.ilcf.org.il



ALCASE Italia: www.alcase.eu

Cittadinanzattiva: www.cittadinanzattiva.it



Women Against Lung Cancer in Europe:
www.womenagainstlungcancer.eu



Cancer Net Japan: www.cancernet.jp

West Japan Oncology Group (WJOG):
www.wjog.jp



Respirando Con Valor A.C:
www.respirandoconvalor.org



Longkanker Nederland:
www.longkankernederland.nl



LungeKreft Foreningen:
www.lungekreftforeningen.no



Esperantra: www.esperantra.org



Associação Portuguesa de Luta Contra o Cancro do Pulmão:
www.pulmonale.pt



Equal Right to Life: www.ravnoepravo.ru

Movement Against Cancer:
www.rakpobedim.ru



Slovenia-NAVDIH (INSPIRE):
www.na-vdih.si



Campaigning for Cancer
campaign4cancer.co.za



Asociación Española De Afectados De Cancer De Pulmón:
www.afectadoscancerdepulmon.com

La Asociación Española Contra el Cáncer: www.aecc.es



Lungcancerforeningen:
www.lungcancerforeningen.se



Forum Lungenkrebs:
www.facebook.com



Formosa Cancer Foundation
canceraway.org.tw



Pembe Hanim: www.pembehanım.com.tr



British Lung Foundation:
www.blf.org.uk

Lung Cancer Nursing UK:
www.lcnuk.org

Roy Castle Lung Cancer Foundation:
www.roycastle.org



CancerCare: www.cancercare.org

GO₂ Foundation for Lung Cancer:
www.go2foundation.org

Lung Cancer Research Foundation:
www.lungcancerresearchfoundation.org

Prevent Cancer Foundation:
www.preventcancer.org

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