

Lung Cancer: A World View

A GLCC project to understand the campaigning priorities in lung cancer at a national level

Introduction

The Global Lung Cancer Coalition (GLCC) serves as the international voice of lung cancer patients. Member organisations have a key focus on lung cancer advocacy, and an important function of the GLCC is bringing members together to converse and exchange ideas.

As a result of the COVID-19 pandemic, the GLCC has been unable to hold a face-to-face meeting for the past two years, and valuable opportunities to exchange information have been lost. The GLCC Lung Cancer: A World View project was initiated to enable members to share their current campaigning priorities and the issues that are most relevant to the patients they represent.

The project consisted of a series of online workshops that gathered insights from a total of twenty-two individuals from twenty-one different member organisations.

The three key themes explored during the workshops were:

1. Access to diagnostics and treatments
2. Screening
3. Recovery of services post-COVID-19

While discussions were framed around these themes, the thoughts and observations shared by members were wide-ranging and offered important insights into the issues faced by their patient populations, and critical areas of focus for advocacy efforts.

Access to diagnostics and to treatments

Across the workshops, there was consistent concern about access to diagnostics and treatments, but the causes of this concern varied widely from country to country. The access issues raised by members from different countries included financial barriers; geographical variations; limited access to new and innovative treatments; access to clinical trials; access to palliative care, including psychological support; and issues with education and awareness.

Financial barriers

While the cost of lung cancer treatment is significant worldwide, differing healthcare systems mean that in some nations this cost is borne by a national healthcare system, while in others, particularly the US, patients bear much of the responsibility. Members from the US described the health system as a “*patchwork*”, noting that with countless different types of insurance, people must advocate for themselves, and often struggle to navigate the system and access the services and treatments they desperately need. Furthermore, while patient access to new and innovative treatments may be better in the US than other nations in theory, in practice, individual patients may not be able to access new treatments if they are under- or uninsured due to high out-of-pocket costs.

Members from the US and South America also noted that financial pressures on patients went far beyond insurance and the costs of treatment and included factors such as transportation. In Peru for example, patients who do not live near a specialised cancer centre must travel significant distances to access diagnostics, treatment, and pain support – for some, the cost is simply too great, and they must forgo treatment and care.



Access to new and innovative treatments

Over the course of the focus groups, a distinct divide was quickly recognisable between North America and the European and Asia Pacific countries represented concerning access to new and innovative treatments. In the US, innovative treatments are for the most part readily available for those who have adequate insurance coverage. Yet for the rest of the world, it is less an issue of individual finances, and rather a problem of delayed approval of treatments, or no reimbursement at all. For example, members from south and central Europe and Asia Pacific expressed concern over the amount of time it took for new treatments to be approved and become available to patients in their countries. In Israel, while patients for the most part have access to medication at no cost to themselves, new drugs are reviewed for inclusion in the health system only once a year, meaning it may take several years from initial drug approval abroad before Israeli patients are able to access newer treatments. Another inequality faced by patients in Israel is the lack of approval, and consequent inability to access immunotherapy for small cell lung cancer.

In countries such as Australia, Brazil, Canada, Israel, and the UK, efforts to minimise delays in drug approval are underway with Project Orbis, a partnership between the US Food and Drug Administration (FDA) and individual nations' equivalent medicine regulatory bodies – a prime example of the importance of international cooperation and its positive impact on patients.

Geographical Variations

Many members shared common concerns about the significance of geographical variations in access and outcomes for lung cancer patients. For countries such as Australia, Italy, Peru and the US, the urban-rural divide is notable, with those in rural areas having far less access to diagnostics, treatment, pain management, and other critical support. These geographical variations could involve access to biomarker testing, the latest treatments, help in navigating the system, and more.

Clinical Trials

Access to clinical trials was also highlighted as limited, particularly in Greece, where there are few clinical trials for lung cancer, and almost none for patients in stages I and II. Even when trials are accessible, many nations, including Greece, have low rates of patient participation relative to availability. Concerns were raised about awareness of clinical trials among patients – those that lived in urban areas such as large cities and had access to larger cancer centres were more likely to receive better assistance in finding and navigating innovative treatments and clinical trials, and in general patients found it necessary to educate and investigate these issues themselves.

Several members detailed their organisation's efforts to inform patients about clinical trials, including creating websites to advertise relevant clinical trials that are available. However, members noted that these websites, although helpful, were difficult to keep up to date and accurate, and required constant management. Our member from Peru highlighted the success of the Peruvian National Institute of Health's (INS) Peruvian Clinical Trials Registry (REPEC): a public website that shares information about all clinical trials available within the country.

Palliative Care and psychological support

Difficulties in accessing palliative care was also raised as a significant issue for lung cancer patients worldwide. In some countries such as Greece, where there is only one hospice centre, palliative care even at the end of life is inadequate or unavailable for most. Many members advised that the lack of access is the result of a culture of thinking of palliative care as end-of-life care rather than management of quality of life. The member from Israel also suggested that as treatments advance and patients are living longer than they would have expected to previously, lack of palliative care presents a growing problem.

Members also noted challenges in accessing psychological support, however reasons for these challenges vary by country. In Spain for example, access to psychological support is recommended in the national cancer strategy, but implementation, and thus access, varies by region. Conversely, in Australia, a main barrier to accessing this type of support is the lack of early referral and long waiting lists of up to six months.

Education and awareness

A lack of education and awareness, both among patients and of healthcare professionals, represented another barrier in access to adequate care. Health literacy was a significant issue raised by members, as patients need to understand their situation before they can ask the right questions and advocate effectively for themselves. Members highlighted the role of patient advocacy organisations, healthcare professionals, and the government in educating patients about their disease and providing them with the appropriate resources to make informed choices about their treatment and care.

Several members reported the difficulty faced by general practitioners in recognising lung cancer symptoms (due to significant overlap between symptoms of lung cancer and other diseases), which often results in late diagnosis and poorer patient outcomes. One member from the UK also suggested that while medical professionals in specialist centres may be able to stay abreast of new and innovative treatments, those in general hospitals were less likely to be aware of these changes. In Taiwan, for example, the case loads of lung cancer managers are heavy, with each manager being responsible for approximately 400 patients. In order to ease the load and improve quality of care, an innovative digital platform is being developed to educate case managers and enable them to share experiences and best practice with one another.

While the causes of barriers in access to diagnostics, treatment, and overall care varied widely from country to country, members revealed a constant concern that lung cancer patients are facing worldwide – the need for patients to consistently advocate for themselves to receive the best care available.

Screening

National lung cancer screening programmes are only established in a small number of countries worldwide, and for many patient advocacy groups, lobbying their government to establish a screening programme is a key focus of campaigning. Screening is critical in lung cancer because late-stage disease has low survival rates, meaning that early detection gives patients the greatest chance of a positive outcome. Members were clear about the need for screening programmes and pointed to examples such as the NELSON trial as evidence of its efficacy in improving outcomes. Most members stated that governments have been slow and even resistant to implement programmes for a range of reasons, such as cost and limited resources, lack of consensus among the healthcare community of its need, and a lack of national data demonstrating the programme's effectiveness within their population.

In Spain, a pilot programme – the Cassandra Project – designed to solve pending questions on lung cancer, including smoking cessation programmes, was recently presented and submitted to the national Ministry of Health with the final aim of obtaining their support for implementation. In the UK, progress has also been made in establishing a lung cancer screening program, with an assessment being undertaken by the National Screening Committee and a recommendation expected soon. In the meantime, screening pilots (the Targeted Lung Health Check Programme) are being rolled out in England. However, one member from the UK raised concerns that a key element in ensuring the success of such programmes is in targeting those at high risk – particularly smokers



and ex-smokers. In the UK, whilst smoking status is recorded by general practitioners (GPs), it is not always accurate. Improving smoking status records, along with securing community engagement to ensure screening uptake, will be important in providing an effective screening program.

In the US, one of the few countries with an established national screening programme, the US Preventative Services Taskforce makes recommendations on who should be screened, yet rates for eligible individuals remain very low. This may be in part due to a lack of national campaigns raising awareness around screening. For smaller patient-centred organisations, resourcing challenges may make it difficult to promote awareness around these programmes.

Globally, government hesitancy represents a substantial barrier to the implementation of lung cancer screening programmes, often based on concerns around cost, ethics, and effectiveness. With many health systems struggling post pandemic, there is a reluctance for policy makers to introduce new areas of work. For the majority of GLCC members, whether their countries have pilot or private screening programmes or none at all, advocacy efforts around the establishment of a national screening programme continue to be a principal focus of their organisation's work.

Recovery of services post-COVID-19

The final theme explored the impact of COVID-19 on patients, healthcare systems, and patient advocacy organisations, and the continued recovery of services. While silver linings included the adaptation to digital and virtual services, members also warned of the longer-term negative impacts of the pandemic.

Long-term consequences of the COVID-19 pandemic

The pandemic limited overall access to care for lung cancer patients in all the countries we interviewed. In Canada, the pandemic led to a reduction in cancer surgeries, with about half of cancer patients recording cancellations of appointments, and local screening programmes also paused.

Most members expressed serious concern that over the next few years, greater rates of late-stage lung cancer would be diagnosed as a result of low rates of early-stage diagnosis during the pandemic.

In terms of healthcare system recovery, members spoke to their widely varying circumstances, with many countries, particularly in Europe and South America, returning to business as usual, and others, such as Ireland and the UK, continuing to struggle with massive backlogs, extensive waiting lists, and an overworked and overwhelmed workforce.

Global Adaptation

Globally, COVID-19 has forced adaptation in the medical community in terms of virtual consultations, which members hope may open access more broadly, particularly when considering geographical variations in access to diagnostics and treatment. Digital and technological advancements have enabled patients to access a range of healthcare services and support, including patient support groups. However, some members noted drawbacks in the introduction of virtual care, which in many general practices across the world, is becoming standard. Our member from Canada noted that most of the patients they speak with are eager to return to in person health checks. Members also raised concerns that the shift toward virtual appointments could be particularly dangerous for lung cancer patients, as it may be difficult to recognise symptoms such as breathlessness via a video or telephone call.

Patient Isolation

Recently, the perception of a shift from pandemic to endemic has raised new questions, with people living with lung cancer wondering how they can continue to protect themselves as the general population transitions back to their pre-COVID ways of living, often overlooking the continued threat of the virus on vulnerable populations. Members reported that patients felt left behind as in many countries, mask wearing and other protective measures are now waning significantly among the general public.

Overall, while the ongoing impact of COVID-19 varied from country to country, there was consensus that the pandemic had led to an exacerbation of existing issues, whether in regard to equity of access, delays in progression and implementation of health policy, or the management of an overloaded health system.

Conclusion

The GLCC's intention in developing the Lung Cancer World View project was to gain a better understanding of the realities and struggles that lung cancer patients are facing, and the similarities and differences in the experiences shared between patient advocacy organisations around the world. While this project revealed substantial insights and suggested many areas for renewed and ongoing attention, including the issue of stigma surrounding lung cancer, a key lesson is the importance of cooperation and exchange of ideas. This project highlighted the value of coalitions like the GLCC that enable organisations from all corners of the world, working on a shared cause, to interact and learn from each other, adapting and incorporating shared lessons in their own work, to ultimately improve patient outcomes and lives.