european cancer ORGANISATION

Leave No One Behind – Delivering Innovation in Lung Cancer Care

ACTION REPORT

Quality Cancer Care Network

The Quality Cancer Care Network is one of the European Cancer Organisation's Focused Topic Networks, established as part of our Strategy for 2020-2023. The Quality Cancer Care Network was launched in April 2020.

More information is available on our website.

If you would like to find out more about the Quality Cancer Care Network, please contact us at: info@europeancancer.org

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The roundtable meeting took its inspiration from the recent publication by the European Cancer Organisation of a new charter for better lung cancer care in Europe, *The Essential Requirements for Quality Cancer Care*: *Lung Cancer.*

Authors

Matti Aapro, President, European Cancer Organisation
Yolande Lievens, Co-Chair, Essential Requirements for Quality Cancer Care: Lung Cancer
Anne-Marie Baird, President, Lung Cancer Europe and Member, European Cancer Organisation's Patient Advisory Committee
Philip Poortmans, Co-Chair, European Cancer Organisation's Quality Cancer Care Network
Simon Oberst, Co-Chair, European Cancer Organisation's Quality Cancer Care Network
Françoise Bartoli, Vice-President, Head of Europe and Canada, Oncology Business, AstraZeneca
Rawa Ismail, Pharmacist, Dutch Institute for Clinical Auditing
Ouzna Morsli, EMEAC Oncology Medical Lead, MSD
Geoff Oxnard, Vice President, Global Medical Lead, Liquid Franchise at Foundation Medicine
Hans J.M. Smit, Chairman, Dutch Lung Cancer Audit

Contributors

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Executive Summary

- Lung cancer poses distinct policy challenges, including its association with late diagnosis and poorer prognosis. Dedicated and targeted policy approaches are required to meet these specific challenges.

- One core approach to improving lung cancer care and treatment is to better ensure people impacted by lung cancer gain access to the full multidisciplinary cancer care team. The newly published *Essential Requirements for Quality Cancer Care*: *Lung Cancer* sets out a fresh and powerful multi-stakeholder consensus about what the lung cancer care pathway consists of. The destination is clear and it must now be achieved.

- Progress in lung cancer screening, molecular diagnosis and tumour profiling provide opportunities for improving lung cancer outcomes, alongside surgery, immunotherapy, chemotherapy and radiation therapy. But barriers to patients accessing these technologies remain. Overcoming these barriers to implementation will require increased understanding about the new opportunities for implementation. It will also require questions that decision makers may still have about their impact on improving outcomes, and cost–benefit, to be comprehensively answered. Emphasis should also be given to developing the skills and experience within the workforce to facilitate adoption of newer technological methods, with the appropriate use of genomic profiling highlighted as a particular example.

- Countries across Europe are also recommended to implement cancer care, including for lung cancer, that utilises quality indicators as tools for continuous improvement. As was emphasised by patient representatives at the meeting *"Information is ammunition for driving and influencing policy changes, as well as driving the optimisation of the care pathway"*.

- At an EU level, politicians recommended an overarching European goal be established to, for example, double survival for poor prognosis tumours such as lung cancer by 2025, to drive change and create political momentum. This should be supported by a European dashboard that regularly and publicly measures progress and success in the EU's fight against cancer.

Introduction

Matti Aapro, President of the European Cancer Organisation

The Community 365 Roundtable Meeting on Lung Cancer, which took place on 7 December 2020, brought together leading policy-makers, politicians, oncology experts, industry partners and advocates to mark the launch of the *European Cancer Organisation Essential Requirements for Quality Cancer Care (ERQCC): Lung cancer*, published in the journal *Lung Cancer*,[1] and to discuss this important area of cancer care.

Lung cancer is typically associated with late diagnosis and, consequently, poor outcomes and high mortality rates. There are challenges around the identification of patients at an early stage in their disease course and in getting patients, once they are diagnosed, into adequate treatment. Moreover, there is a stigma around the disease that stems from a lingering assumption that it is self-inflicted.

Despite this, there have been great strides in the diagnosis, assessment and management of lung cancer in recent years, with the introduction of immunotherapy and innovations in the molecular diagnosis and profiling of tumours, leading to the development of effective targeted therapies. Together, these offer patients the opportunity to receive innovative treatments with greater benefits and lower toxicities than traditional therapy combinations.

Yet patients all across Europe face issues in accessing these innovations due to variations not only in their availability but also in the organisation of care. This means many do not reap the rewards of decades of research and are left with suboptimal care. The result is that the potential for improvements in lung cancer outcomes and survival is not being realised.

In response, the European Cancer Organisation developed the *ERQCC: Lung Cancer*, the latest in our series of publications on the Essential Requirements for Quality Cancer Care.[2] Written by European experts representing all disciplines involved in cancer care, including our Member Societies, as well as patient representatives, the ERQCC papers provide roadmaps to high-quality multidisciplinary cancer care, which is at the heart of the European Cancer Organisation's guiding mission:

"To reduce the burden of cancer, improve outcomes and the quality of care for cancer patients, through multidisciplinarity and multiprofessionalism".

Access to Quality Care

The Community 365 Roundtable Meeting opened with a presentation and discussion of the *ERQCC: Lung Cancer*. This sets out how it aims to help countries bridge the gap in providing access to multidisciplinary management for lung cancer patients by focusing on care pathways and appropriate timelines, the multidisciplinary team, and performance indicators, among other key aspects. In this sense, it provides 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 care throughout the patient journey.

This was followed by a session, co-chaired by Françoise Bartoli, Vice-President, Head of Europe and Canada, Oncology Business, AstraZeneca, on the need for early diagnosis and screening in lung cancer. This highlighted how, although questions remain over what form screening should take on the ground and how to target and recruit the most appropriate individuals, implementation roadmaps need to be developed across Europe to improve early diagnosis rates.

Next, there was a session on molecular diagnostics in lung cancer and its relevance for appropriate treatment selection, co-chaired by Geoff Oxnard, Vice President, Global Medical Lead, Liquid Franchise at Foundation Medicine. This focused on next generation sequencing of tumours and liquid biopsies, which offer the opportunity for greater precision in the diagnosis and profiling of lung cancers. This can be used in many cases to guide treatment and better characterise a patient's prognosis. However, equitable access to these technologies, as well as the overall care framework in which they are used, remains an issue all across Europe.

Finally, a case study on the importance of quality indicators was presented in a session co-chaired by Ouzna Morsli, EMEAC Oncology Medical Lead at MSD. This looked at the Dutch Lung Cancer Audit, which has grown over the past few years to include all patients with lung cancer in the Netherlands and has already begun to have an impact on key measures of quality care.

Through success stories such as these, and by making screening and innovations in diagnosis and tumour profiling available to all patients across Europe, we can make a real difference to the lives of lung cancer patients and their families. They cannot wait any longer. The time is now.

Essential Requirements for Quality Cancer Care: Lung Cancer

Yolande Lievens, Co-Chair of the *Essential Requirements for Quality Cancer Care: Lung Cancer*, opened the first session by highlighting that the incidence of lung cancer in Europe in 2018 was 365,000 individuals, while mortality reached almost 300,000.

Moreover, prognosis remains poor, with five-year survival rates very low. While the incidence of lung cancer is higher in Western and Northern European countries, the mortality ratio is far higher in Eastern and Southern Europe.

There are opportunities for improvements in the prevention and management of the disease but they remain insufficiently exploited. This will require the better organisation of healthcare to ensure access to multidisciplinary management to drive up both the quality of prevention and care and better outcomes.

The *Essential Requirements for Quality Cancer Care (EQRCC): Lung Cancer*[1] aim to help countries bridge that gap. Written by experts representing all disciplines involved in cancer care in Europe, the paper gives patients, healthcare professionals and policy makers a guide to essential care throughout the patient journey.

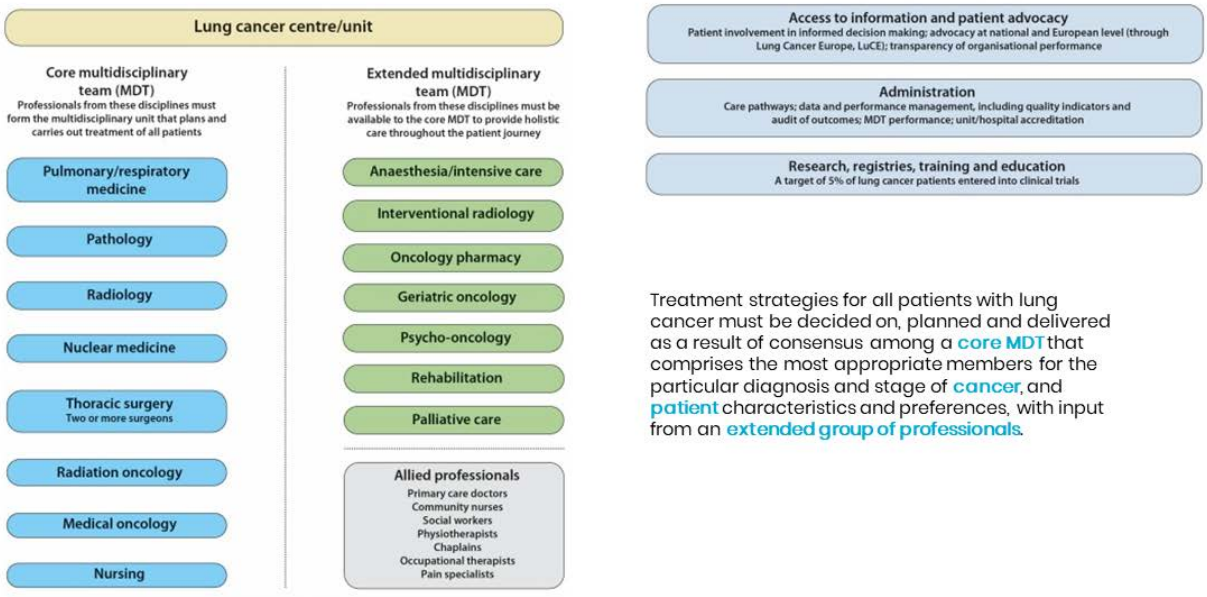
The paper helps cancer centres and healthcare professionals structure and organise care to bring optimal treatment to their patients. The paper gives recommendations on pathways and timelines, on what a cancer centre should look like, the composition and requirements of the core and extended multidisciplinary team (MDT), on patient involvement, performance indicators, and research and education, among others.

They also highlight the challenges around lung cancer. These include the high rate of diagnoses at advanced stages, for which, besides prevention, screening may be a solution alongside improved awareness and education. It sets out strategies to improve primary care and emphasises the complexity of diagnosis and staging.

Optimal treatment is challenging, however, as patients may be older and have comorbidities, and care should be tailored to their needs. The psychosocial needs of people with lung cancer are frequently neglected compared to other cancers, which is partly linked to the stigma surrounding the disease, due to it being often seen as self-inflicted.

Crucially, the quality of care must be measured. Centres must develop performance metrics and

Figure 1. Defining the core and extended MDT



quality indicators based on the *EQRCC: Lung Cancer* and on clinical guidelines, in line with national and legal requirements.

Operational policies are needed to ensure the benefits of a coordinated clinical pathway are realised, alongside effective data management and reporting systems, engagement with patients, their carers and support groups, and accountability over governance processes.

Above all, the *EQRCC: Lung Cancer* should not remain a static endeavour but be continuously updated to integrate optimised treatment and health system approaches.

Ambitious Engagement

In the following discussion Irena Joveva MEP (Slovenia, Renew Europe) said that 2020 has been marked by ambitious engagement by the European Parliament on cancer policy, with numerous committees and legislative files dedicated to the fight against cancer. However, as access to screening and early diagnosis, as well as cancer survival, is often associated with an individual's place of birth, there is a need for greater involvement on a European level.

Closing the gaps between countries and regions can be achieved, and Joveva recommended an EU goal be established of doubling survival for poor prognosis tumours such as lung cancer. She hopes that the EU4Health programme[3] will support this aim, and would allow for a Europe-wide cancer dashboard, giving particular attention to lung cancer.

While the impact of the COVID-19 pandemic on screening programmes has made the fight against cancer harder, Joveva believes change is possible, and thanked the European Cancer Organisation for its work in helping to improve cancer care.

Acknowledging the Psychological Impact

Anne-Marie Baird, President of Lung Cancer Europe and Member of the European Cancer Organisation's Patient Advisory Committee, said the *EQRCC: Lung Cancer* could have a huge impact all along the care pathway, and agreed that it must continue to evolve.

Cooperation will be key to implementing screening, as although there have been policy changes across Europe, they have not been widely implemented. Early detection, on the other hand, relies heavily on education and awareness for both the public and medical professionals. It is not acceptable that any part of the care pathway delays diagnosis or treatment, as people impacted do not have the luxury of time. Access to best care cannot wait.

Baird also stressed the huge psychological impact of lung cancer, and the issues around access to support, as well as the financial toxicity associated with cancer.

She welcomed the emphasis in the Essential Requirements on securing access for the patient to the multidisciplinary team (MDT) but stressed this was too often not the reality experienced by patients. Metrics should be used to demonstrate improvements in care, and allow patient groups to lobby for better care. Information is ammunition for driving and influencing policy changes, as well as driving the optimisation of the care pathway.

Lievens said she fully agreed with the points raised by Baird, and said she is looking forward to collaborating to turn them into action.

Early Detection and Screening

The session was co-chaired by Matti Aapro, President of the European Cancer Organisation, and Françoise Bartoli, Vice-President, Head of Europe and Canada, Oncology Business, AstraZeneca. Bartoli began by underling that everyone taking part in the Roundtable meeting shared a common vision to build a better future for lung cancer patients.

She noted that the EU Mission Board for Cancer set a target of saving three million lives by 2030. [4] However, lung cancer accounts for one in five deaths worldwide, and any reduction in mortality will have a significant impact on overall cancer deaths. The past few years have seen considerable advances in treatment options for lung cancer, yet the prognosis remains very low.

While there are clearly challenges, there are also opportunities, and progress will transform lives. Targeted screening and early detection programmes have been piloted in some countries, such as France, Germany and the UK, and there is a move towards national implementation across Europe. However, the COVID-19 pandemic has intensified the need to act urgently, as any delays will have an enormous impact further down the line.

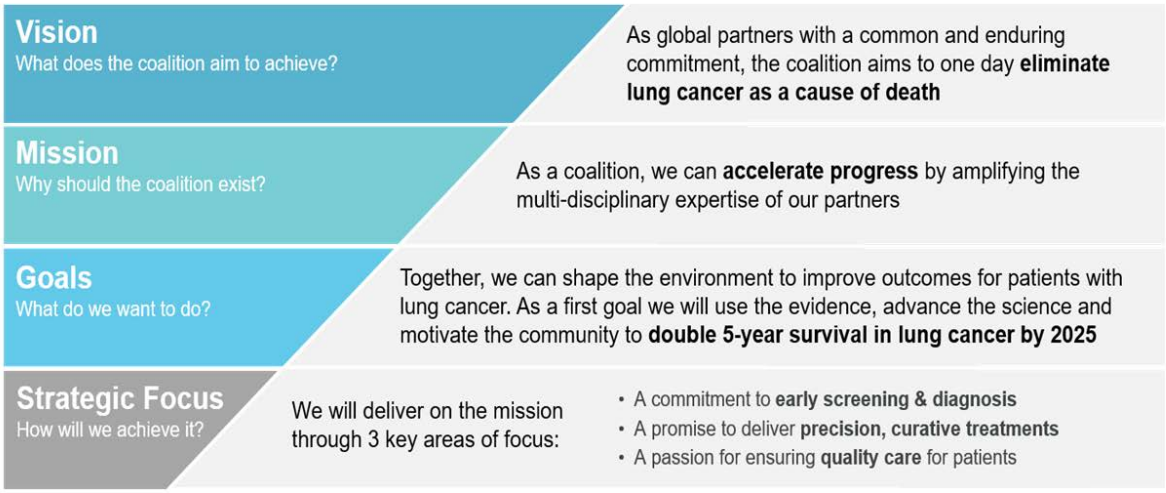
Collaboration Key to Tackling Lung Cancer

Giorgio Scagliotti, Professor of Medical Oncology, University of Turin and Chief of the Medical Oncology Division at the S. Luigi Hospital, is Past President of the International Association for the Study of Lung Cancer (IASLC). He explained that accelerating advances in lung cancer care requires collaboration, and that is at the heart of the current strategic plan of the IASLC.

Lung cancer remains a huge challenge, however, with almost two million people dying from the disease worldwide every year. While five-year survival of patients with stage I/II disease is around 60%, only just over a quarter are diagnosed in early stages. In contrast, 40% of patients are diagnosed in stage IV, when five-year survival is 10% or less.[5,6]

Scagliotti explained that the IASLC is currently gathering data for the ninth edition of the TNM Classification for lung cancer, due in 2024. This will include, for the first time, information on gene alterations and protein expression, at least in a subgroup of patients included in the database, with the aim of achieving more precise diagnosis and treatment and, ultimately, improved patient survival.

Figure 2. Lung Ambition - the Mission



In addition, the Lung Ambition Alliance has been launched,[7] for which the IASLC has joined forces with industry partners and no-profit organisations to accelerate progress towards eliminating lung cancer as a cause of death, with the initial goal being to double five-year survival by 2025. This will be underpinned by a focus on early screening and diagnosis and the delivery of precision, curative treatments, as part of quality healthcare.

Scagliotti emphasised that results from screening trials have shown that, despite the different methods and models used across the various studies, mortality is reduced by 20%–40%. However, key issues remain, despite the evidence from randomised controlled trials, the optimal screening frequency, the potential for over-treatment and over-surveillance, the long-term outcomes, as well as unresolved questions about the role of biomarkers.

One of the major barrier to screening uptake remains the lack of awareness and understanding of its benefits and effectiveness, particularly among primary care physicians. There are also ongoing considerations around the planning and implementation of screening, such as the identification of high-risk, hard-to-reach populations, public recruitment to and engagement with screening, differences in lung cancer incidence between men and women, and the cost-effectiveness of combined screening and smoking cessation.

Some of these issues are being explored by the Early Lung Imaging Confederation (ELIC),[8] which aims to integrate deep learning and artificial intelligence approaches towards the early detection of lung cancer. This includes image analysis and stratification and it will represent a research tool to identify patients requiring non-invasive biomarker studies or invasive procedures. There are also a number of promising lung cancer screening biomarkers under investigation, including nucleic acids, cells, proteins and other molecules detectable in the blood, bronchoscopy samples, sputum and exhaled breath, among other sources.

Another initiative, the Major Pathologic Response project, will combine recommendations on standardised tissue processing and pathologic assessment with big data to use major pathologic response as a surrogate marker for survival.

These and other projects, such as ILC2,[9] and TERAVOLT,[10] aim to leverage enhanced data sharing and analysis to identify tumour characteristics that be used to ultimately improve the survival of lung cancer patients.

A Window of Opportunity

In the following discussion, Frances Fitzgerald MEP (Ireland, EPP) said the COVID-19 pandemic has been very challenging in terms of cancer care but has led to a debate over EU legal competencies to act in areas of health policy, which may offer future opportunities to improve pan-European collaboration on topics such as lung cancer. Indeed, there is a new emphasis and desire to work together on health in general and on cancer in particular, as illustrated by the forthcoming Europe's Beating Cancer Plan,[11] and the numerous committees working actively in this area.

She believes that there is a window of opportunity, and a great deal of motivation, to build bridges and share research, information and best practices to develop the best policies to tackle the challenges faced in cancer care. Key to this are multi-stakeholder groups and partnerships, alongside awareness campaigns to translate specialist knowledge and research for the public.

Breast cancer is a great example of this but lung cancer is currently lagging behind. More work is therefore needed in this area. Cancers are generally considered blame-free but lung cancer is often seen as self-inflicted, and patients may blame themselves for their illness. This has to be tackled, while making sure that young people understand the risks of smoking.

Fitzgerald hopes that Europe's Beating Cancer Plan will help to bring the best of European research to patients, especially as many EU Member States are slow to implement innovations. The aim must be to use the lessons of the COVID-19 pandemic to bring people and organisations together to drive improvements in lung cancer care.

Preparing the Ground for Screening

Helmut Prosch, from the European Society of Radiology, agreed with those sentiments, saying that if the international and local efforts in the fight against COVID-19 were repeated for lung cancer, there could be huge strides in diagnosis, treatment and care.

He underlined that lung cancer screening requires collaboration not just between patients and clinicians but also with politicians, especially in tackling the stigma surrounding the disease. The supportive evidence is already there, but implementation studies are required to convince clinicians and policymakers of its worth.

Jan van Meerbeeck, from the European Respiratory Society, echoed those comments, saying that, although screening should be considered the standard of care in lung care, the issue remains its implementation.

Scagliotti observed that lung cancer screening should be used as a preventive measure in those considered at high risk but said he would not advocate starting screening in community hospitals right away, as the right framework is required and the ground needs to be prepared. However, he emphasised that the pandemic has shown what was considered impossible just one year ago is seen as possible today, and so the initiative should be seized to take these efforts forward.

Implications Further Along the Treatment Pathway

Marc Beishon, co-author of the *Essential Requirements for Quality Cancer Care*: *Lung Cancer*, commented that screening could raise issues further along the treatment pathway as, if it becomes widespread public policy, it will have implications for lung cancer centres by increasing patient numbers.

Yolande Lievens, Co-Chair of the *Essential Requirements for Quality Cancer Care*: *Lung Cancer*, agreed, saying that how to address the availability of resources needed for treatment will have to be considered. She also underlined Fitzgerald's comments on awareness over the risks of smoking, not least in younger people, as it remains of the utmost importance as a key pillar in the fight against lung cancer. Moreover, it is supported by all professionals in the field.

In closing, Bartoli said the session showed that, despite the variety of perspectives, there is clearly a very strong commitment to the early detection and screening of lung cancer.

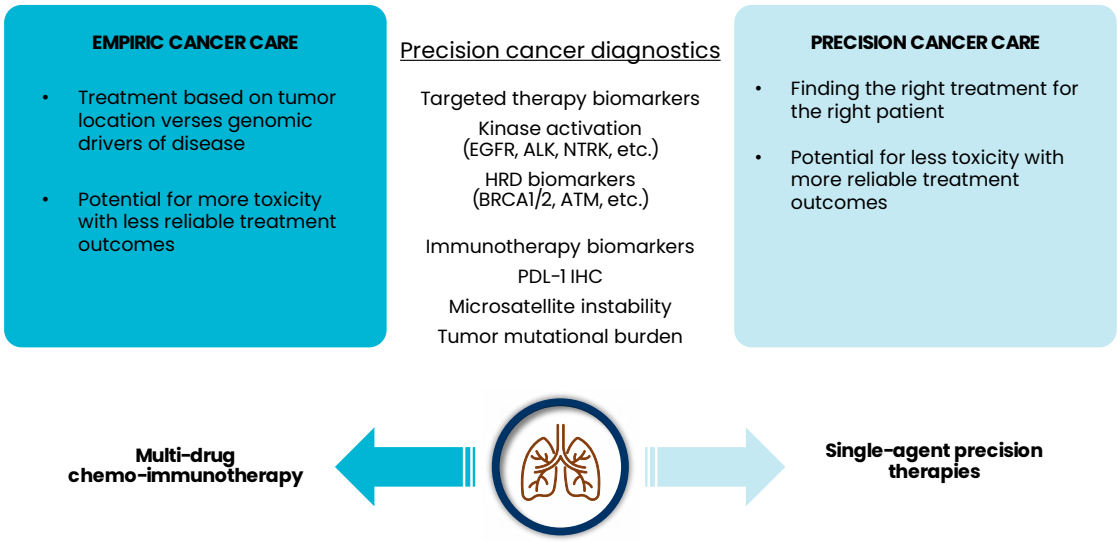
Molecular Diagnostics in Lung Cancer – Considerations and Relevance for Treatment Selection

The third session of the Roundtable Meeting was co-chaired by Matti Aapro, President of the European Cancer Organisation, and Geoff Oxnard, Vice President, Global Medical Lead, Liquid Franchise at Foundation Medicine.

Oxnard opened by underlining the need to transition patients away from empiric cancer care, in which treatment is guided by tumour location rather than the genomic drivers of disease, and towards precision cancer care, which involves finding the right treatment for the right patient.

Lung cancer is the ideal candidate for this kind of shift as, without precision diagnostic testing, patients end up receiving multiple therapies with the potential for greater toxicity and less reliable treatment outcomes, all at a greater overall cost than if they were given single-agent therapy with greater benefits and less toxicity. The question is, however, how to implement that shift.

Figure 3. Precision cancer care & precision cancer diagnostics



A Revolution in Understanding

Matthew Krebs, Clinical Senior Lecturer in Experimental Cancer Medicine, University of Manchester and Consultant in Medical Oncology, The Christie NHS Foundation Trust, Manchester, UK, explained that, traditionally, lung cancer was considered and classified in terms of its histology, divided into non-small cell and small cell lung cancer with further histological subtypes for non-small cell lung cancer, besides being characterised for the use of immunological approaches.

There is now a greater understanding of the disease, and with the revolution in genomic profiling the number of sub-classifications has risen from just three in non-small cell lung cancer in 2004 to more than 25 today. These advanced diagnostics have led to the identification of numerous actionable genetic alterations via genomic profiling, such as in the EGFR, ALK, ROS1, RET and TRK genes, thus allowing precision treatment to be chosen. For patients, this has meant a dramatic revolution in the care of lung cancer and other disease types, with novel oral medications achieving fantastic responses and improved survival.

Several genetic alterations are therefore recommended for testing, as well as many more that should be assessed depending on the availability of next generation sequencing, as

discussed by organisations such as the European Society for Medical Oncology.[12] Few of those tests are actually performed in routine clinical practice, however.[13] Moreover, Krebs said that the availability of testing is likely to be highly variable across different centres.

Even when genomic testing is performed, centres typically use older technologies. While they work well, there needs to be a step change towards broad panel testing by next generation sequencing. This combines testing for all potential genetic actionable alterations in one panel with data aggregation and analysis, and expert review to provide a curated, quality-controlled report to help physicians identify targeted or immunotherapy treatment options.

The implementation of next generation sequencing, however, is dependent on the availability of resources, Krebs said, as it is not just a question of a sample being loaded onto a machine. He underlined that expert input is required to reliably interpret the results and determine whether they are significant. This has been a likely factor in delaying more widespread adoption in the clinical setting.

Another aspect affecting the take-up of molecular diagnostics in lung cancer is the question of tissue versus liquid biopsy. Tissue-based genomic profiling remains the standard of care, due to its higher sensitivity for certain types of alterations, but frequently there may not be enough material for molecular testing, the obtaining of biopsies is itself challenging and poses risks to the patient, and tissue biopsies do not capture the heterogeneity of the tumour.

Liquid biopsy has, on the other hand, evolved enormously in recent years and can help in profiling patients, as a reliable result can be obtained simply by drawing a blood sample. This can be analysed by extracting tumour-derived DNA, with results turned around usually within 10–14 days. Due to its simplicity, it could, be applied at various steps along the care pathway, from screening and initial diagnosis (although highly sensitive technologies would be required for this purpose) and prognostic assessment to therapy response monitoring, detection of resistance mechanisms and recurrence surveillance. It is also able to better capture tumour heterogeneity compared with single site biopsies. However, it will not provide answers for all patients, Krebs noted, and tissue biopsy testing consequently remains important. The two are complementary.

For some patients who do not have identifiable genetic alterations, immunotherapy has become a back-bone of therapy in non-small cell lung cancer. There is, however, a lack of good biomarkers for selecting patients who are most likely to benefit from this therapy. Assessing the tumour mutational burden may help in identifying patients who could benefit from immunotherapy as monotherapy. Together with genetic profiling in liquid biopsy, this can help inform clinical decision making in non-small cell lung cancer and guide patients to targeted versus immuno- and chemotherapy, as is being investigated in the ongoing B-FAST trial.[14]

Krebs said that the question nevertheless remains as to how to integrate these advanced diagnostic tools into routine clinical practice.

Quality of Testing is Key

In the following discussion, Joanna Chorostowska, Secretary General of the European Respiratory Society, said that, while there is a tight link between molecular diagnostics and diagnostics per se, the quality of the testing is key, as that determines the quality of treatment. Crucially, the higher the quality of the sample, the better the results.

She said that the *EQRCC: Lung Cancer*[1] is fundamental, as it highlights the complexity of the clinical process and the need to come together to provide high quality services all along the cancer pathway. Within that, the MDT should be much more than a meeting over a few hours but the basis for the effective organisation of healthcare.

Chorostowska also underlined that, while pathological examination enables the diagnosis of lung cancer type and, optimally, its subtype, molecular diagnostics enable the detection of predictive biomarkers that direct therapeutic

decisions. They therefore offer very different types of information. Molecular testing consequently does not replace pathological assessment and will not for the foreseeable future.

Empowering Patients

Next, Anne-Marie Baird, from Lung Cancer Europe, underlined the inequalities in the availability of molecular diagnostic testing both between and within countries, and that huge advances in technology are not always translated to the clinic in an acceptable timeframe. In addition, a proper biomarker needs to be associated with every drug to maximise benefits and minimise toxicities.

Alongside that, it remains the case that simply many people do not know what type of lung cancer they have, whether or not their tumour has undergone genetic testing, let alone whether the result was positive or negative. Clinical communication should be very clear; if not, it means that people may look for information elsewhere and a general search for lung cancer would yield overwhelming results. People with lung cancer also need to be empowered to ask the most pertinent and important questions about testing, treatment and their overall care.

A Hopeful Future

Addressing Baird's observations on the inequalities around the availability of molecular testing, Marc Beishon, co-author of the *Essential Requirements for Quality Cancer Care*: *Lung Cancer*, noted that the approach of the paper is to map the organisation and resources needed to deliver the current, and essential, standard of care, which many do not receive.

Simon Oberst, Co-Chair of the European Cancer Organisation's Quality Cancer Care Network, remarked that it would be interesting to know the health economics of liquid biopsies and next generation sequencing, while Jan van Meerbeeck, from the European Respiratory Society, questioned whether liquid biopsy should be available to all patients, without prescription.

Closing the session, Oxnard said that the discussion has left him hopeful as, despite the stigma surrounding lung cancer, there is optimism over innovative medicines becoming more available for patients, even those with the most advanced disease. Innovative testing will also allow for more precision care. Yet access to these innovations is key, and tests need to be leveraged to provide patients with more information.

The Dutch Lung Cancer Audit: Nationwide Quality of Care Evaluation Using Quality Indicators

The final session was co-chaired by Matti Aapro, President of the European Cancer Organisation, and Ouzna Morsli, EMEAC Oncology Medical Lead at MSD.

Morsli began by saying that progress is being made in addressing the burden of lung cancer. Mortality is falling thanks to reductions in the incidence of the disease and its better management, with greater advances in treatment in the last five years than in the previous twenty.

Nevertheless, a report by the Economist Intelligence Unit showed that there are opportunities for the improvement of care in all countries, with around half of lung cancer guidelines not including fast-tracking of suspected lung cancer patients for diagnostic testing, a specific timeframe for obtaining testing nor rapid referral of newly diagnosed patients for treatment.[15]

There are also delays in lung cancer care all along the pathway. There is therefore a need for the development and implementation of quality indicators, and for the results to be audited.

Insights into Lung Cancer Care

To demonstrate what can be achieved, Hans J.M. Smit, Pulmonologist at Rijnstate Hospital, Arnhem, Netherlands, presented the Dutch Lung Cancer Audit, of which he is Chairman, alongside Rawa Ismail, PharmD and PhD Candidate at the Dutch Institute for Clinical Auditing (DICA).

Smit said the Audit is a multidisciplinary, government-funded register under the umbrella of DICA that began in 2016 and has evolved in the intervening years to cover surgery, radiotherapy and medical therapy. It aims to offer insights into the quality of lung cancer care by focusing on, for example, diagnostics, time to diagnosis and therapy, therapy outcomes, and the provision of best supportive care.

Quality indicators are established by the scientific committee and external parties, such as healthcare insurers and the Dutch Health Care Institute, and are based on national quality standards and evidence-based guidelines. In total, 15 quality indicators were implemented to improve processes and clinical outcomes.

The Audit, which receives data from more than 40,000 lung cancer patients from 73 hospitals throughout Netherlands, has needed to overcome some specific implementation challenges, Smit noted. This has included working to contain the time needed to input data, to ensure control over how the inputted data is processed, and generally to ensure maintenance of privacy standards.

Improving the Quality of Care

Ismail said that the Audit has nevertheless successfully included all Dutch patients with lung carcinomas, as well as those with suspected disease, gathering data on 153 variables, of which over 40% are mandatory.

The results, the first of which were published in 2020,[16] show that the completeness of the dataset has increased over time, and only two hospitals are seeing fewer than the recommended minimum number of patients.

Crucially, there have been improvements in care over the course of the Audit. For example, the proportion of stage III non-small cell lung cancer patients undergoing brain imaging increased from 82% in 2017 to 90% in 2019, and the proportion of stage IV adenocarcinoma patients receiving molecular diagnostics increased from 89% to 93% over the same period.

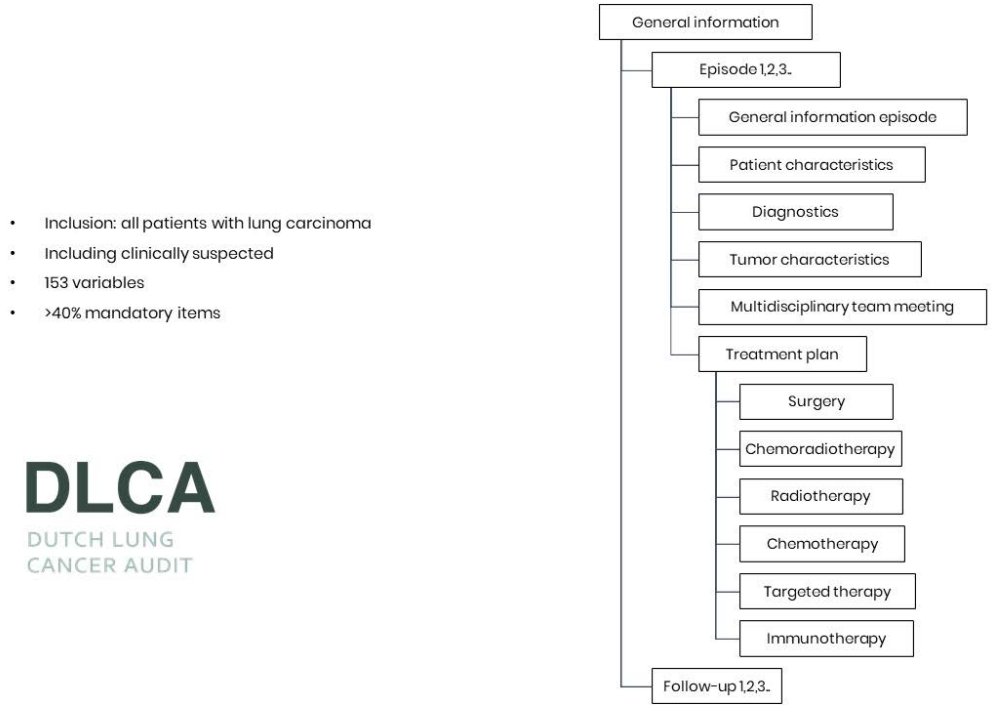
The Audit also showed the time from diagnosis to starting treatment was less than 21 days for 62% of patients without invasive mediastinal diagnostics and 46% of those who had endoscopic or endobronchial ultrasound scan, and less than 35 days for 59% of those who had mediastinoscopy.

What this means for clinical practice is that, via standard setting and data analysis, the Audit improves the quality of tumour information and management recommendations, which, combined with patient values and preferences, improves shared decision-making.

Smit said the Audit also shows that, while quality registries play an important role in quality care improvement, and benchmarking with other hospitals can offer best-practice examples, it takes time to initiate a nationwide registry.

It is also important to start small in terms of the number of quality indicators to minimise the burden on hospitals. Nevertheless, indicators on hospital processes can lead to indirect improvements in care and, while outcome measures are of high value, they should be measured only when the registry data are rich and reliable.

Figure 4. The DLCA dataset



An Inspiring Example

In the following discussion, Aapro said that the Audit is a wonderful example of what everyone in lung cancer care could achieve, while Helmut Prosch, from the European Society of Radiology, said benchmarking is important to optimise care pathways and help discussions, and should be rolled out Europe-wide. He underlined that it is only by following best practice that outcomes will improve.

Asked whether patient-reported outcomes are included in the Audit, Smit confirmed that they are, but explained it is not easy to analyse them as survival has historically been very poor in lung cancer. The team are nevertheless looking at ways to integrate them into the registry.

In closing, Morsli said she hopes the Audit will inspire others and, while awaiting Europe's Beating Cancer Plan, cancer dashboards, including care quality indicators, should be further explored, and collaborations to improve care continued.

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As the not-for-profit federation of member organisations working in cancer at a European level, the European Cancer Organisation convenes oncology professionals and patients to agree policy, advocate for positive change and speak up for the European cancer community.

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european cancer ORGANISATION

Rue d'Egmont 13
B-1000 Brussels, Belgium

+32 2 775 02 00

europeancancer.org

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