european cancer ORGANISATION

Closing the Response Gap for People Living with Metastatic Cancer

ECO Policy Action Report



Acknowledgements

This report draws on the input of experts from across Europe and beyond, and their presentations, contributions and recommendations that were shared at the European Cancer Organisation (ECO) Community 365 Roundtable Meeting 'Metastatic Cancer: Driving Enhanced Policy Response', held online on 5 May 2026.

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b. Find more information concerning the report here: https://www.europeancancer.org/events/426:community-365-roundtable-metastatic-cancer-driving-enhanced-policy-response.html

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Executive Summary of Recommendations

The recommendations below set out, in brief, the priority calls to action arising from the roundtable

On meeting the needs of people with brain metastases

- Currently, cancer registries across Europe are failing to record the true incidence and prevalence of brain metastases. This critical data gap must be addressed with greater urgency by national registries. This would ideally be achieved by a coordinated European effort supported by relevant EU funding and programme mechanisms as part of an overall effort to heighten EU oncology data systems.

  Mechanisms for Policy Action include: The EU's Digital Health Agenda, including the implementation of the European Health Data Space; EU Joint Action activities relating to cancer registries; Member State national cancer control plans.

- Palliative and supportive care too often remain late considerations in a patient's pathway. Health systems should be more accountable for providing earlier access to such care, including for those recently in receipt of a diagnosis of metastasis of a cancer to the brain. Raising public and professional awareness of integrated palliative oncology care is essential, including educating both the public and professionals on the true nature of palliation and the need to include it early in the cancer trajectory, rather than only at the end of life.

  Mechanisms for Policy Action include Member States, health systems & clinical leaders – via national cancer strategies, clinical guidelines and service planning.

- Patients with progressing or leptomeningeal brain metastases are too often excluded from clinical trials. This situation should be addressed jointly by trial sponsors, regulators, HTA bodies and other interested stakeholders. The inclusion of patients with progressing leptomeningeal and brain metastases should be encouraged and incentivised, and every relevant trial protocol should discuss the sponsor's decisions on their inclusion or exclusion.

  Mechanisms for Policy Action include improved EMA guidance to trial sponsors, regulators and ethics committees.

- There are system-level reasons why investment in brain metastases research has been less forthcoming from private sources of finance. The need to direct and support public and academic funding towards brain metastases research is therefore significant.

  European Union, Member States, European research institutions – via the next Multiannual Financial Framework for 2028-2034, dedicated funding calls and research programmes.

- Significant improvement options for patients with brain metastases are emerging, including specialist radiotherapy techniques such as stereotactic radiosurgery. Efforts will be required to support enhanced access to such options across Europe, including the potential for greater cross-border healthcare options.

  Member States & health systems – via national and regional service planning, reimbursement and workforce investment.

- For a clinical trial environment for brain metastasis to flourish, it is necessary to achieve greater standardisation in trial terminology and endpoint acceptance so that research on brain metastases has firmer foundations for acceptance and progression.

  Research bodies, clinical trial sponsors – via consensus standards, trial protocols and reporting guidance.

On improving communication about a metastatic diagnosis

- Healthcare and oncology professionals require greater support in knowing and deploying the most appropriate communication with patients about a metastatic diagnosis. Training every clinician who delivers a metastatic diagnosis in standardised communication skills, such as the SPIKES protocol or the Serious Illness Conversation Programme (SICP), could make a significant contribution to improvement.

  Health systems, professional bodies and medical education providers – via undergraduate, postgraduate and continuing professional development requirements.

- It must be recognised that a metastatic diagnosis is a reality to be communicated to a patient over time, not in one single conversation. Beyond the treating physician, nurses, pharmacists and other healthcare professionals in regular communication with a patient should also be equipped and supported in communicating to a patient about their diagnosis.

  This is a call to: Health systems, clinical leaders and professional bodies -– via care pathways, multidisciplinary team standards and workforce training.

- There is a general identified need for more informational resources that can support patients and healthcare professionals in understanding the realities and implications of a metastatic diagnosis well beyond the moment that the diagnosis is communicated. This includes advice to support individuals in the management of the impacts upon work, finances, family and other components of personal daily life.

  Health systems, professional bodies and patient organisations – via the development and routine provision of accessible information.

- Health systems that respond more to patient-reported outcomes and experiences will be more successful in raising standards of care. This is especially true for patients with metastatic cancer, where needs are not otherwise sufficiently addressed.

  Health systems & policymakers – via national quality frameworks, patient-reported measures and accreditation standards.

- Words matter. Continual use of war, battle, and fight metaphors by the media and others in describing cancer can be unhelpful or even hurtful for those personally experiencing cancer. This can be all the more the case after a patient receives a diagnosis of metastatic cancer. Does anyone really wish, however unintentionally, to convey an idea that an individual is 'losing their war'? Greater sensitivity in use of language by all can help to reduce unintended and unnecessary psychological burdens on individuals with metastatic cancer.

  Governments, public health bodies, NGOs, media organisations and journalists – via public communication strategies, guidance and professional standards.

On addressing the social and legal implications of metastatic cancer

- The social and economic dimensions of living longer term with metastatic/advanced cancer must be more fully reflected in national cancer plans and strategies. This includes supporting patients in their return-to-work needs and ensuring carers' needs are recognised and addressed.

  Member States & national policymakers – via national cancer control plans, social protection policies and employment strategies.

- Countries can, and should, do more to strengthen and harmonise legal protections for the employment rights of people with metastatic cancer, moving beyond employer discretion towards enforceable legal entitlements. For example, access to flexible work arrangements should not depend solely on an employer's goodwill but be supported by clear legal rights and obligations.

Member State legislators & social partners – via employment law, equality legislation and collective agreements.

- Active consideration should be given in all countries to ensure that definitions of disability in disability protection legislation clearly include people living with metastatic or incurable cancer. This can have the practical and positive effect of supporting patients with such issues as employment protection, parking and access to services.

  Member State legislators & disability policy authorities – via disability and equality frameworks.

- Informal carers for patients with metastatic cancer consistently experience under-recognition and inadequate financial support. This should be addressed by recognising and supporting informal carers, including through financial support and formal recognition of their caregiving role. This could include legislative entitlements such as dedicated paid carer leave, flexible work rights, income support measures, and obligations on governments and public services to provide support for carers and recognise their needs in policy development and service delivery.

  Member States & social protection authorities – via carer legislation, social security systems and care policies.

- Work participation should be measured as a routine patient-reported outcome. It should be further established as a significant health outcome and indicator of quality of life.

  Member States, clinical bodies & health systems – via clinical guidelines, research protocols and health outcome frameworks.

- Employing organisations should ensure workplace cultures that support employees with metastatic cancer to fulfil their potential and avoid the possibility of quietly sidelining those with workplace adjustment needs. This could be supported by measures, including organisational cancer policies that promote consistent, supportive and equitable responses.

  Employers, HR professionals & line managers – via workplace policies, training and collective agreements.

Introduction

A growing number of people across Europe are now living for years with metastatic cancer. Policy has yet to catch up with them. As more people live for years, even decades, with advanced cancer, they face a distinct set of challenges that current policy frameworks are not designed to address, including treatment, research, survivorship, social and quality of life. This also requires ensuring appropriate access to the full range of evidence-based systemic and local treatment options, delivered within a multidisciplinary care pathway.

On 5 May 2026, the European Cancer Organisation convened a Community 365 Roundtable to confront this challenge, uniting patients, clinicians, researchers, industry and policymakers around a single goal: turning growing awareness into concrete policy action. Co-chaired by Fatima Cardoso, President of the ABC Global Alliance and Kathy Oliver, Chair of the International Brain Tumour Alliance, the discussion made one thing clear: a fundamental shift in mentality is now needed, from clinical practice to policymaking, to ensure that people living with metastatic cancer are no longer left behind.

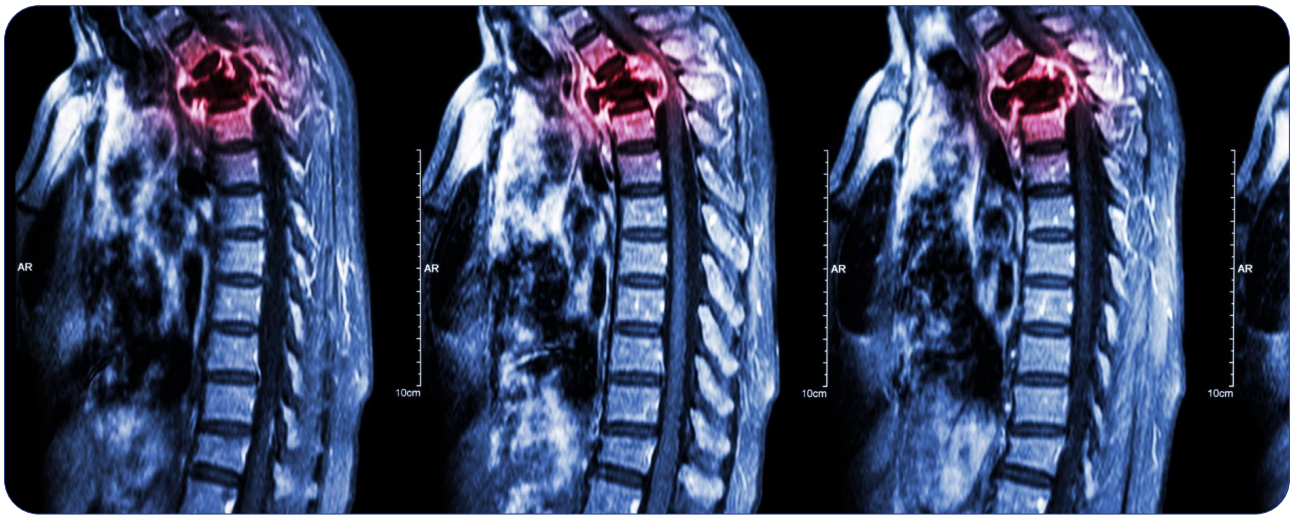
Opening the meeting, Member of the European Parliament Billy Kelleher (Ireland, EPP) struck a note of both progress and urgency. Europe's Beating Cancer Plan and the EU Research Mission on Cancer, he noted, have rightly put survivorship on the European cancer policy map. However, they are only a starting point, not a destination. He pointed to his own work for a European 'right to be forgotten', aiming to ensure cancer survivors are no longer penalised by financial service providers, and warned this protection must not become a postcode lottery. He also issued a pointed call to action: without systematic data on metastasis and recurrence in Europe's cancer registries, policymakers are navigating blind.

The roundtable was structured around three themed sessions: metastasis to the brain, communication to patients and families about a metastatic diagnosis, and the social and legal implications of living with metastatic or advanced cancer. A summary of the roundtable discussion and the resulting policy recommendations follows.

> **Across Europe, we still do not systematically measure cancer metastasis or recurrence in our cancer registries. This gap limits our ability to fully understand and respond to patient needs.**
>
> **Billy Kelleher MEP**

Definitions:

In this report, metastatic cancer refers to cancer that has spread from where it first started (the primary site) to other parts of the body. Advanced cancer is used more broadly for cancer that is unlikely to be cured, including metastatic cancer and some cancers that have grown extensively where they started. Neither term should be read as synonymous with death and dying: a growing number of people now live with metastatic cancer for many years, often under continuous treatment.



Session One: Metastasis to the Brain

Co-chaired by Fatima Cardoso, President, ABC Global Alliance, and Francesca Bargiacchi, Global Head of Medical Strategy for Solid Tumours, Menarini Stemline.

Building bridges in a sparse landscape

Kathy Oliver, Chair and Co Director of the International Brain Tumour Alliance (IBTA), described brain metastases as a field calling out for new structures and stronger bridges between disease communities. She notably described the different challenges faced by patients, healthcare professionals, as well as by the pharmaceutical industry and research community more generally.

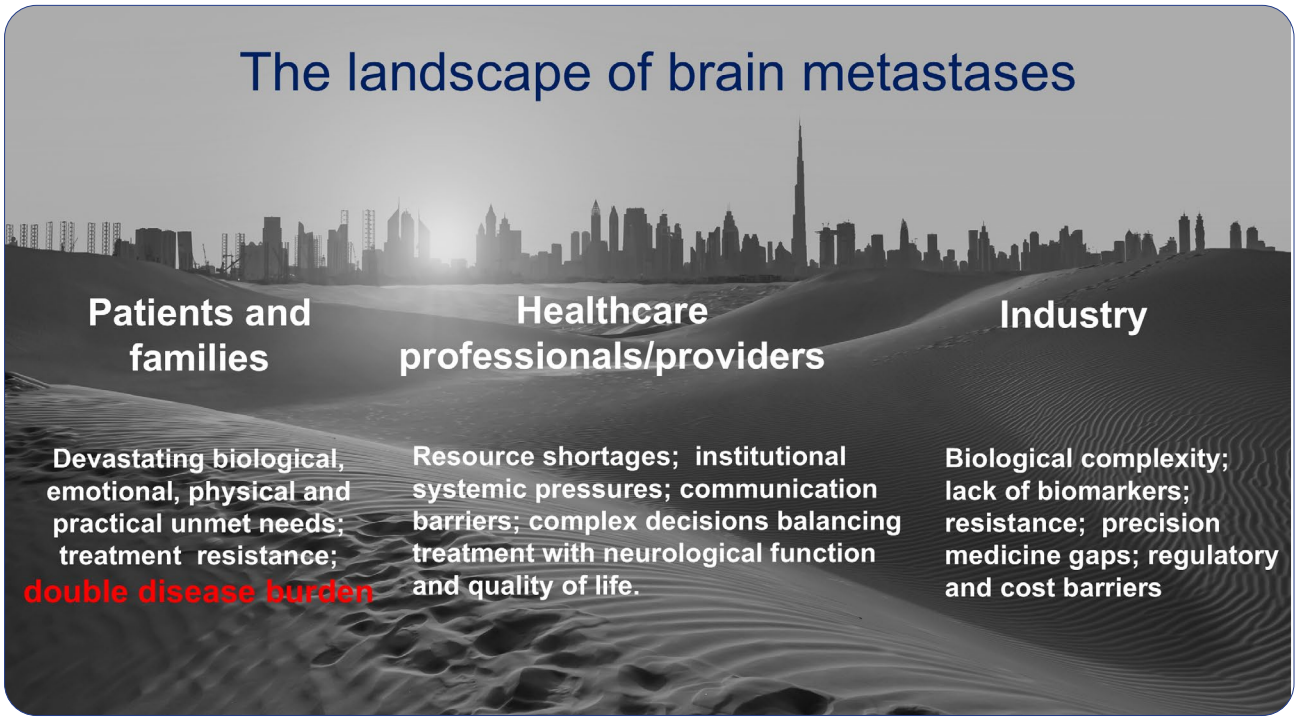
On the one hand, patients face a double disease burden, confronting the biological, emotional and practical needs of both their primary cancer and their brain metastases. On the other hand, healthcare professionals face systemic pressures and the difficulty of balancing survival, neurological function and quality of life in a fragile patient population. Industry also faces the considerable challenge of developing therapies able to cross the blood-brain barrier, alongside the biologically heterogeneous nature of brain metastases and complex regulatory pathways.

> **Brain metastases patients find themselves in a really tough double disease burden landscape as they confront the devastating biological, emotional, and practical needs which come along with this diagnosis.**
>
> **Kathy Oliver,**
> International Brain Tumour Alliance

In response to this set of challenges, the IBTA, in collaboration with the American Brain Tumor Association (ABTA), organised in 2023 a one-day international patient advocacy symposium on brain metastases in Vienna. The 'Vienna symposium' produced a wish list of actions, including:

- Giving patients with progressing brain metastases, and not only those with stable disease, access to clinical trials
- Providing regular proactive screening for brain metastases
- Increasing treatment and research funding for innovative therapies
- Speeding up drug and treatment approvals
- Addressing the emotional distress and psychological challenges faced by patients
- Helping caregivers cope with the physical, cognitive and emotional effects
- Improving access to supportive care
- Enhancing coordination of care and communication between providers and patients
- Delivering better access to existing information
- Creating registries for brain metastases patients
- Eliminating stigma, discrimination and therapeutic nihilism

Figure 1: The landscape of brain metastases, American Brain Tumor Association presentation



Findings from the ABTA survey on metastatic brain tumours

Dr Nicole Willmarth, Chief Mission Officer at the American Brain Tumor Association (ABTA), addressed the scale of unmet need in brain metastases.

Dr Willmarth explained that a diagnosis of brain metastases often comes as a profound shock, frequently prompted by sudden symptoms, such as a severe headache or a seizure. For some patients, the shock is compounded by the fact that they are many years past their original cancer diagnosis and had never discussed with their care team the possibility that their cancer could spread to the brain. Historically, brain metastases carried a grim prognosis, with median overall survival measured in months. Nevertheless, outcomes are continuously improving, with the creation of innovative solutions, such as targeted therapies and immunotherapies.

In 2017, the ABTA launched a survey of over 200 patients living with brain metastases, together with caregivers and treating clinicians, published in Neuro-Oncology Practice in 2021. The survey shed light on important issues:

- A clear gap between physicians, who generally believed they had discussed brain metastases sufficiently with their patients, and patients and caregivers, who often could not recall having received this information, pointing to a

> **Care for brain metastasis patients is deficient, inconsistent, and fractionated, and there's a lot more that we can do to help support these patients.**
>
> **Nicole Willmarth,**
> American Brain Tumor Association

real opportunity to improve physician-patient communication.

- Patients and caregivers reported wanting more honest and detailed discussion of prognosis, treatment options, clinical trial availability and patient advocacy support, information that was frequently not raised in clinic.
- The most common patient reported symptoms following diagnosis were headache, cognitive changes, ongoing fatigue and balance problems, some of which were not identified by physicians as leading concerns.
- Neurocognitive decline was identified as a major worry for patients, linked both to the tumours themselves and to treatments such as whole-brain radiotherapy.
- For most patients, the primary goal of care was preserving quality of life rather than cure.
- Despite guidelines and evidence linking palliative care to improved survival, only around 17.5% of patients had seen a palliative care physician during their treatment.

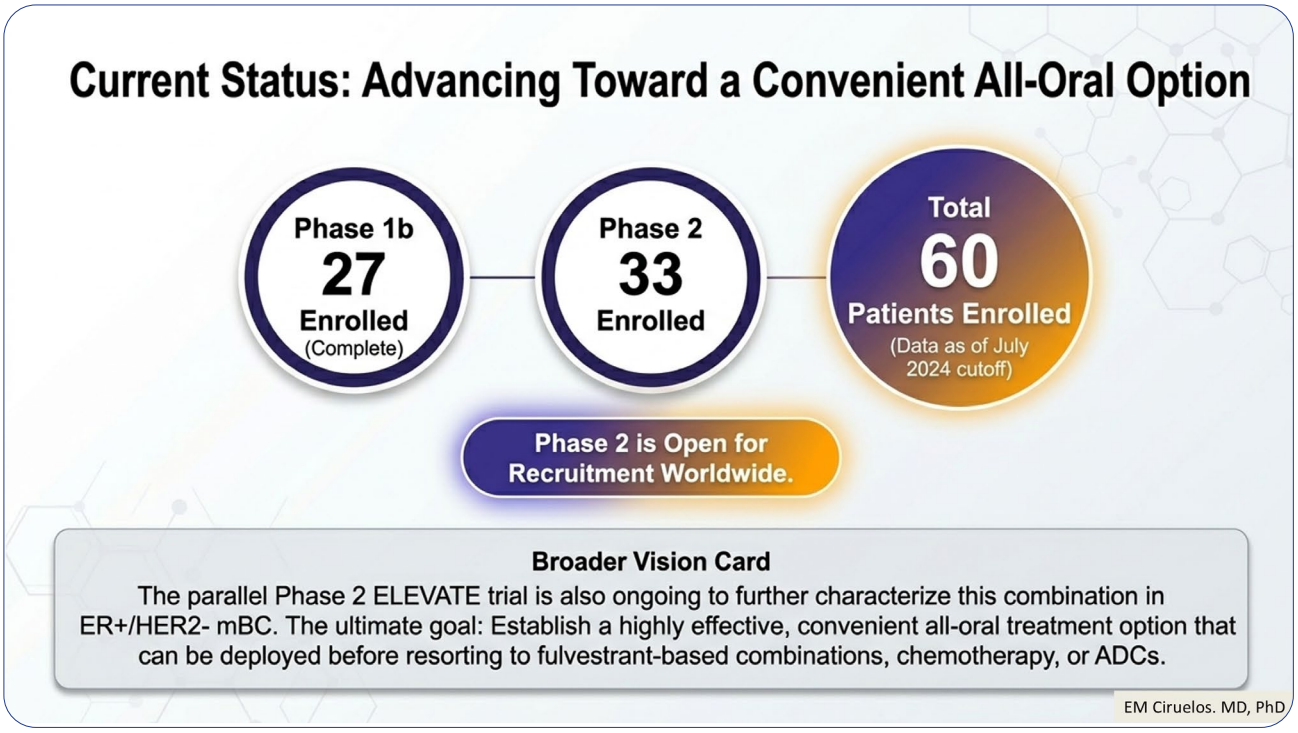
Taken together, Dr Willmarth concluded, the findings show that care for people with brain metastases remains inconsistent and fragmented, with considerable scope to improve support for this population.

An example of Innovation for brain penetrant treatment: the ELECTRA trial

Dr Eva Ciruelos, Medical Oncologist at the Hospital Universitario Doce de Octubre in Madrid and Chair of the SOLTI Breast Cancer Research Group, presented on the ELECTRA trial, which is testing a new treatment combination specifically designed to reach brain metastases in a group of patients who have had few options built for them.

Dr Ciruelos explained that combinations of endocrine therapy with CDK4/6 inhibitors (palbociclib, ribociclib and abemaciclib) are the current standard first- and second-line treatment for luminal, ER-positive, HER2 negative advanced breast cancer, the most common form of the disease. The problem is that around 30 to 40% of patients on this standard treatment develop an acquired resistance mechanism linked to ESR1 mutations, meaning the treatment eventually stops working. Newer drugs called estrogen receptor degraders, including elacestrant, already offer a more effective option once this resistance develops and are now available across most of Europe, but they do not, on their own, address a further, often overlooked problem facing this group of patients: getting treatment into the brain.

Figure 2: Current status of the ELECTRA trial, Eva Ciruelos' Presentation



Most research into brain penetrant breast cancer treatment has focused on HER2-positive or triple-negative disease, since these subtypes are more likely to spread to the brain. But around 30% of advanced luminal disease can also develop brain metastases, and these patients have effectively been left behind. This is because the blood-brain barrier blocks most drugs, including chemotherapy, from reaching the tumour, which results in poor prognosis and a significant decline in quality of life, with few alternatives available once the disease reaches the brain.

Dr Ciruelos described the ELECTRA trial, combining elacestrant with abemaciclib in an attempt to overcome both problems at once: resistance to standard treatment, and the blood brain barrier. Early results are encouraging, with 57% of patients in the trial seeing a clinical benefit by 24 weeks. This matters because it shows the approach is safe enough to study further in exactly the patients who need it most. Having already passed its first safety and efficacy checkpoint, the trial is continuing to recruit towards a total of 60 patients with brain metastases, a meaningful step towards a treatment option designed for a patient group that current drugs largely fail to reach.

Closing the research gap: academic collaboration on brain metastases

Dr Evangelia Razis, Director of the 3rd Oncology Department at Hygeia Hospital in Athens and a member of the executive board of the Breast International Group (BIG), spoke on the contribution of academic research to improving treatment and care for people with brain metastases. She described her work with the BIG Brain Metastasis Task Force, which brings together patients and physicians from Europe, North and South America, Asia and Australia.

Dr Razis explained that pharmaceutical industry interest in brain metastases research remains limited, meaning academic research must answer the questions that matter most to patients. These go well beyond treatment efficacy to include optimal screening strategies, balancing different approaches and their cost, how far treatment can be de-escalated, and health-related quality of life.

Drawing on work with the Breast International Group Brain Metastasis Task Force and collaborators in North America, Dr Razis described the development of a white paper on research needs in brain metastases, developed with patient input. This paper calls for greater use of real-world data, ensuring patients with active brain metastases are included in trials, clear definitions of terms such as active and asymptomatic disease, agreed time points for brain imaging, and the use of CNS-specific trial endpoints, given the particular difficulty of measuring response in the brain. Where trials exclude patients with brain metastases, the reasons should be clearly explained, and screening data should still be collected.

Measuring treatment response within the brain poses particular statistical challenges. Following stereotactic radiosurgery, clinicians may observe pseudo progression, where imaging appears to show the disease worsening even though the patient is in fact benefiting from treatment, complicating the choice of trial endpoints. Dr Razis illustrated this with the design of a recent EORTC trial, where it was unclear how to classify patients whose disease progressed systemically but not intracranially, since such patients would otherwise come off study before intracranial progression-free survival could be captured. Addressing these methodological gaps, she argued, is as important as expanding access to research itself.

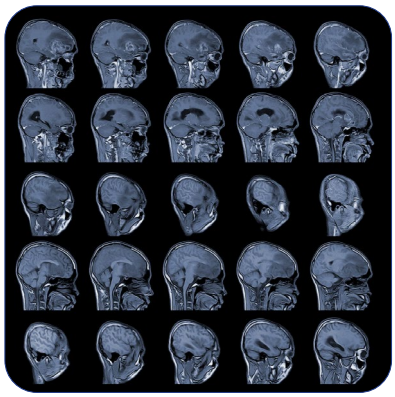
Closing the session, Fatima Cardoso highlighted continuing inequities in access to clinical trials, particularly for patients with leptomeningeal disease who are systematically excluded, and in access to high-quality radiotherapy, including stereotactic radiosurgery, noting that such inequities exist not only between countries but also within them.

Policy Recommendations from Session One

- Counting what matters, by establishing population level registries to finally capture the true incidence and prevalence of brain metastases across Europe
- Embedding palliative and supportive care early and consistently into the treatment pathway, not as a last resort
- Including patients with progressing or leptomeningeal brain metastases in clinical trials as standard, and clearly explaining and documenting any exclusion
- Investing public and academic funding into brain metastases research, to close the gap left by limited industry interest
- Equalising access to specialist radiotherapy techniques, such as stereotactic radiosurgery, across and within every country
- Standardising trial terminology and endpoints so that research on brain metastases can finally be compared and built upon







Session Two: Communicating a Metastatic Diagnosis

Co-chaired by Kathy Oliver, Chair and Co-Director, International Brain Tumour Alliance, and Michael Zaiac, Head of Medical Affairs, Oncology, Europe and Canada, Daiichi Sankyo.

A deeply human moment

Debra Montague, President of Lung Cancer Europe (LuCE) and herself an ALK positive lung cancer patient living with brain metastases, opened the session by describing the communication of a metastatic diagnosis as not a clinical conversation but a deeply human moment. Good communication has a proven impact on patient satisfaction, adherence and psychological outcomes, yet studies show that patients recall only between 40% and 60% of a conversation once they have received devastating news. This notably implies that giving a metastatic diagnosis cannot be a single conversation. It needs to happen over time and involve more than one healthcare professional, with nurses able to check understanding and continue the conversation in follow-up appointments.

Ms. Montague argued that the absence of formal communication training for clinicians on such an important aspect of care amounts to a systems failure. She set out principles that should underpin such conversations: they should be person-centred, clear and honest, while always offering realistic hope, empathy and dignity.

She introduced the SPIKES approach to communicating difficult news, covering:

- **Setting** (ensuring an appropriate, private setting for the conversation)
- **Perception** (checking what the patient already understands or perceives)
- **Invitation** (inviting the patient to say how much they wish to know)
- **Knowledge** (sharing information clearly and checking understanding)
- **Emotions** (responding to the patient's emotional reaction with empathy)
- **Strategy and summary** (agreeing next steps, since there is always a next step)

Other evidence-based communication tools are also available. The Serious Illness Conversation Programme (SICP), developed by Ariadne Labs, is already used in many EU countries.

Ms Montague argued that if all clinicians adopted this simple approach, it would raise the standard of care across Europe. Good communication, she concluded, is when a patient leaves a consultation

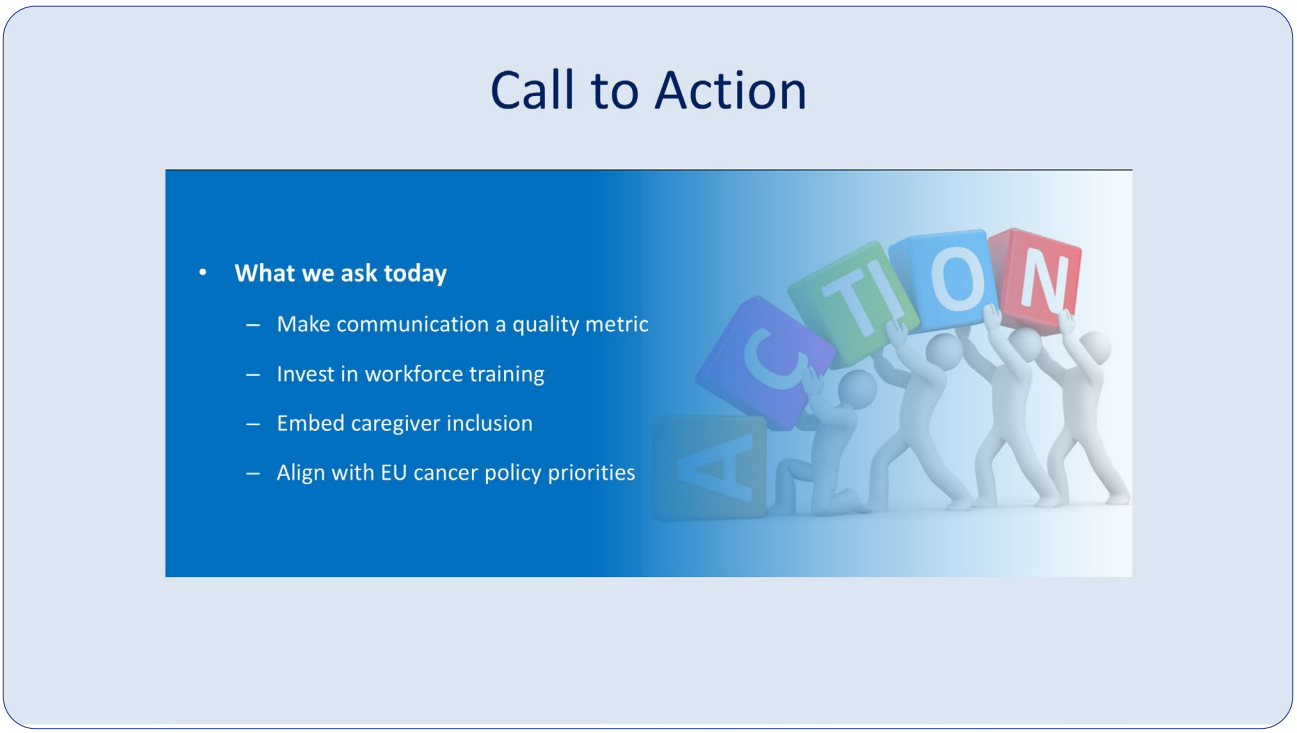
> **Caregivers so often are left in the dark, left out of the conversations. A metastatic diagnosis is just as devastating for the caregivers as it is for the patient.**
>
> **Debra Montague,**
> Lung Cancer Europe

understanding their situation, engaged in next steps, and able to make decisions about their own care, with caregivers included as part of the team. She called for mandatory communication training for all clinicians, standardised protocols embedded within Europe's Beating Cancer Plan, multidisciplinary training extending to nurses and pharmacists, patient-friendly resources, and the measurement of communication quality through patient-reported experience measures, so that communication becomes a recognised quality metric.

Figure 3: The SPIKES' method, Debra Montague's Presentation



Figure 4: Recommendations for improved communication, Debra Montague's Presentation



The power of words in public discourse

Maria Nomikou, Director of the Hellenic Cancer Federation (ELLOK), addressed the impact of language used around cancer in the media and public discourse. She noted that language in Greece, as in many countries, is often dominated by war metaphors, references to battles and to winning or losing, which can create pressure on patients and lead to feelings of failure or guilt, reinforcing stigma and a culture of fear that can deter people from screening or seeking care.

> **The language around cancer is not only a matter of semantics. It is a fundamental issue in public health and human dignity.**
>
> **Maria Nomikou,**
> Hellenic Cancer Federation

In response, ELLOK launched The Power of Words, a collaborative initiative between patient organisations, academia and the Greek state. A preliminary survey found that 88% of respondents were negatively affected by the term 'incurable disease'and that phrases such as 'I lost the battle' are experienced as deeply burdensome. suggesting personal failure. Patients and families consistently asked for respect and scientific accuracy, as well as for a shift towards person-centred language that emphasises quality of life rather than heroism or drama.

Ms Nomikou explained that next steps would include a further survey of journalists, analysis by academic partners at Panteion University, development of a media guide, and exploration of specialised courses for journalism students, with the involvement of patients and families and the support of the Greek General Secretariat of Communication.

The role of the European Code of Cancer Practice

Peter Selby, Consultant Physician at St James's University Hospital and principal author of the European Code of Cancer Practice, presented the ongoing update of the Code. Co-produced by equal numbers of patients, patient advocates and professionals, the Code sets out ten highlighted areas covering the whole patient journey, including early and accurate diagnosis, accurate, relevant and understandable information, equal access to the best multiprofessional care, equitable care in all locations, shared decision-making, integrated supportive and palliative care, a focus on quality of life, access to research and innovation, planning for survival and integration back into normal living, and access to high quality end-of-life care.

> **You should feel free to question, that you are empowered to challenge your professionals when need be.**
>
> **Peter Selby,**
> St James's University Hospital,
> European Code of Cancer Practice

He highlighted two areas of particular relevance to metastatic disease: accurate, relevant and understandable information, and shared decision-making. Adoption of shared decision-making indeed remains patchy across Europe, with only some countries formally requiring it, despite clear evidence of its benefits for the quality of decisions

taken and for the patient's overall quality of life and emotional wellbeing. The updated Code, due to be launched at the European Cancer Summit in November, is designed to empower patients to question their healthcare professionals and to ask why they are not receiving access to the rights it identifies.

The psychological dimension

Tania Estapé, Vice President of the International Psycho-Oncology Society (IPOS) and Director of Psycho-Oncology at FEFOC in Spain, noted that a review of national cancer plans found that only 41% include psycho-oncology, meaning psychosocial needs remain far from adequately embedded in patient care overall. She explained that the psychological experience of metastatic disease differs from that of an initial cancer diagnosis. Patients are described as incurable but treatable, facing lifelong treatment and side effects, and a shift from fear of recurrence to fear of progression.

Dr Estapé stressed the importance of respecting the patient's emotions rather than imposing what she termed 'the tyranny of positive thinking'. She also encouraged addressing and discussing the guilt that patients often feel about the impact of their illness on family and caregivers. She observed that metastatic patients are more often affected by depression than anxiety, linked to the loss of the ability to make plans, and described the need to help patients build realistic, achievable goals, described as a 'micro life'. She emphasised the importance of promoting hope in a realistic way, encouraging structured daily routines and adapted physical activity.

Policy Recommendations from Session Two

- Training every clinician who delivers a metastatic diagnosis in standardised communication skills, such as the SPIKES protocol or the Serious Illness Conversation Programme (SICP)
- Recognising that a metastatic diagnosis is meant to be communicated over time, not a single conversation, with nurses and pharmacists equipped and included throughout
- Developing patient friendly resources that support understanding of a metastatic diagnosis well beyond the moment it is delivered
- Measuring communication quality through patient reported experience measures, so it becomes a recognised standard of care
- Reshaping public and media language on cancer, moving away from battle metaphors towards accurate, person centred communication





Session Three: Addressing the Social and Legal Implications of Metastatic Cancer

Co-chaired by Fatima Cardoso, President, ABC Global Alliance, and Maria Isabella Grueso, Pfizer.

> **We need policies that protect these patients who live a relatively long-term disease and have very specific challenges in terms of survivorship and quality of life.**
>
> **Fatima Cardoso,**
> ABC Global Alliance

A global mapping of work rights for cancer patients

Sarah McHutchison, Legal Policy Advisor at the McCabe Centre for Law and Cancer, explained that metastatic cancer often gives rise to preventable legal, employment and financial harms. This may include persistent workplace exclusion, the cumulative burden of out-of-pocket costs, the invisibility of informal carers, and, in countries without 'right to be forgotten ' laws, delayed or denied access to financial products. These experiences engage fundamental rights, including equality and freedom from discrimination, the right to freely chosen work, an adequate standard of living, and social security.

Ms McHutchison referenced ABC Global Alliance's 2024 patient survey, which found that 73% of respondents reported a negative impact on their ability to work or study, whilst 16 % had lost their job directly due to metastatic breast cancer, and nearly a third of those still working reported inadequate workplace support. A 2024 UK study also found that only 4% of employers had cancer-specific workplace policies in place, and that even where policies exist, a persistent gap remains between policy intent and practical implementation.

Flexible working arrangements were highlighted as critical to enabling patients and carers to remain in or return to work. Ms McHutchison referenced the EU's 2019 Work Life Balance Directive which provides workers with caregiving responsibilities a 'right to request', though not an absolute right to, flexible work as an important first step.

> **While some countries provide strong legislative protections in some key areas, none has introduced a comprehensive set of workplace entitlements sufficient to protect the work rights of people with metastatic breast cancer.**
>
> **Sarah McHutchison,**
> McCabe Centre for Law and Cancer

From law to lived reality

Reflecting on this presentation, **Dr Fatima Cardoso** highlighted that provisions left to employer discretion, without accompanying government support, often fail to translate into real-world protection. She notably referred to Goal 10 of the ABC Global Alliance Charter and the need for people with advanced breast cancer to see improvements in their legal rights and their right to return to work.

Dr Cardoso also noted that in some countries, specific types of cancer are treated as equivalent to disability for legal and social protection purposes and suggested this could be a route to improved protection for people with metastatic cancer, while cautioning that this should not be applied as a blanket approach to all cancers, given that nearly one in two Europeans will develop cancer in their lifetime and may face stigma. She also stressed the importance of considering the needs of caregivers, who sometimes give up paid work to provide care.

Also responding to the presentation, **Maria Isabella Grueso** described the European Advanced Cancer Working Group, comprising 12 patient advocacy representatives from across Europe with global input, which is developing a European policy white paper that translates unmet needs into practical, policy-oriented recommendations, prioritised according to urgency, feasibility and impact. Ms Grueso explained that the initiative grew out of a recognition that policy responses for people living with advanced cancer needed to be strengthened, and that doing so meant first understanding, systematically, what patients themselves identified as the most pressing gaps. She was explicit about the reasoning behind keeping the list short and practical: the people affected need action within a realistic timeframe, not a lengthy policy agenda that takes years to move.

Nicole Sheehan, President of the Global Colon Cancer Association, was then invited to reflect on how the Advanced Cancer Working Group's discussions resonated with her own experience in patient advocacy. She noted that although members of the group differ widely in cancer type, geography and type of organisation, a consistent set of themes kept surfacing:

- Patients face ongoing uncertainty that doesn't resolve after diagnosis
- How a diagnosis is first communicated matters, but so does the quality and clarity of information patients receive over the entire course of their illness
- Patients consistently want to be active participants in decisions about their own care, not simply told what has already been decided for them
- Financial strain and out-of-pocket costs exist in some form in every health system, even the best-resourced ones
- Caregivers are frequently left out of the conversation entirely, despite a cancer diagnosis affecting the whole family

Turning to system-level gaps, Ms Sheehan also pointed to supportive and palliative care not being integrated early enough in treatment, inconsistent access to biomarker testing, and care that is poorly coordinated across specialties and treatment modalities, including systemic and local treatments, leaving patients to navigate a system that is not always designed around their needs.

Ms Sheehan noted recent encouraging developments and solutions being implemented, citing patient navigation models such as EU Navigate in Europe and dedicated navigator roles at medical institutions like Johns Hopkins in the US, which help patients and caregivers move through the system with real support.

The economic and human case for supporting work

Veronica Foote, Head of Policy and Consulting at Working with Cancer, focused her presentation on the gap between legal protection and lived experience.

Legal protection, she argued, is necessary but not sufficient. She cited the example of the UK Equality Act, under which cancer is treated as a disability from the point of diagnosis, and where employers must make reasonable adjustments. She nonetheless observed that a metastatic diagnosis can still quietly end career progression, often driven by unconscious bias and assumptions that a person with metastatic cancer cannot cope or commit. Workplace culture, leadership and, above all, line manager behaviour are what most shape a person's experience at work. Ms Foote also set out the economic case for supporting people to remain in work, noting that inaction has real costs, including lost skills, productivity and tax contributions, increased dependency on welfare systems, and additional pressure on health systems as financial stress and isolation worsen health outcomes.

> **A metastatic diagnosis can quietly end career progression. Promotions don't happen, development opportunities fade away, and people are moved into smaller roles.**
>
> **Veronica Foote,**
> Working with Cancer

Ms Foote proposed addressing what she termed the 'PROM gap': work participation is rarely measured as a patient-reported outcome, with questions on whether people were able to stay in work, how quickly they returned, what happened to their income, and their career trajectory rarely asked. She recommended including work participation as a patient-reported outcome, particularly in real-world evidence studies, to build the evidence base on the functional and economic impact of treatment and to establish work as a legitimate health outcome in its own right, alongside survival.

Ms Foote finally observed that national cancer plans rightly focus on prevention, diagnosis, treatment and survival, but rarely address what comes after, such as whether a person can keep their job or meet their financial commitments. While Europe's Beating Cancer Plan represents an important step forward, its implementation remains uneven, and people with metastatic cancer are often excluded from key provisions, such as the right to be forgotten, since this right has little meaning for someone whose cancer is ongoing. She called for a clear policy focus on employment protections, support for carers, workplace standards and accountability.

Recommendations from Session Three

- Addressing the social and economic dimensions of survivorship in national cancer plans, including employment, financial stability and support for carers
- Strengthening and harmonising legal protections for the work rights of people with metastatic cancer, moving beyond employer discretion towards enforceable entitlements
- Considering disability equivalent status for specific metastatic or incurable cancers, applied carefully to avoid stigma or blanket use
- Recognising and supporting informal carers, including through financial support and formal carer status
- Measuring work participation as a routine patient reported outcome, to establish it as a legitimate health outcome alongside survival
- Training employers, HR teams and line managers to build workplace cultures that support, rather than quietly sideline, people with metastatic cancer

Conclusion

Closing the roundtable, the discussion underscored an urgent truth: the challenges facing people living with metastases can no longer wait. The data gap in cancer registries must be closed, biomarker testing must be properly funded, clinical trials must be reformed, and people living with brain metastases deserve stronger quality of life and legal protection.

Delivering this requires sustained collaboration across cancer types and across every stakeholder group. This work continues through the European Cancer Organisation's Survivorship and Quality of Life Network, with further discussion expected at the 2026 European Cancer Summit in Brussels and online, on 18 and 19 November, under the theme Strengthening Cancer Care: Securing a Healthy, Equitable, Resilient and Competitive Europe.

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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