

Activity Report

2024: A YEAR IN REVIEW



WECCAN

Workgroup of European
Cancer Patient Advocacy Networks

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WECAN Overview

The Workgroup of European Cancer Patient Advocacy Networks (WECAN) is a network of 24 dedicated umbrella cancer patient advocacy organisations operating across Europe.

WECAN represents cancer patients from all indications, uniting efforts at a pan-cancer level to drive meaningful improvements and advocate for change that benefits every patient.

Our thriving network, founded in 2015, is now transitioning into a Foundation as it prepares for its 10th year, marking a significant milestone in our mission to strengthen and expand our impact across Europe.



Mission

Our mission is to improve the outcomes for all cancer patients by acting as a well-coordinated cancer patient community towards all stakeholders by building levels of trust, collaboration, alignment, and mutual support in the pan-European cancer patient community.



EDUCATION

WECAN offers patient advocates and organisations valuable programs and resources to develop their knowledge and skills.



RESEARCH

WECAN advances cancer advocacy through a research-driven approach tailored to cancer patients across all indication areas. By leveraging robust data, it ensures that evidence-based initiatives align with patients' needs and outcomes are effectively communicated to enhance engagement and maximise impact.



POLICY

WECAN enhances cancer advocacy in Europe by fostering collaboration, driving joint actions, and addressing needs through policy, research, and capacity building. These efforts aim to improve outcomes for cancer patients.

A Letter from the Chair

Dear all,

Last autumn (2023), I was honoured to be elected as the Chair of WECAN for 2023-2024, which I was personally very pleased about. I would like to take this opportunity to share some of our key highlights of 2024 with you.

In January, we held a very successful Evidence-Based Advocacy (EBA) workshop in which 40 participants, including patient advocate trainees, experts, clinicians, industry stakeholders, and researchers, took part. This workshop also laid the groundwork for the Cancersurvey, particularly shaping the design from the perspective of various indications.

Once a year we meet for a retreat, and during this year's retreat, we decided to establish ourselves as a legal entity in the form of a Foundation. I would like to thank our members and emphasise that this has been a long, well thought-through democratic process. With this decision the to-do list has become long, from changing the statutes (approved by the members) to revising the governance! But we managed it with a team that had the determined objective of bringing this process to a positive conclusion by the end of the year. We are also pleased to announce that we have been able to win trustees and elect a new Management Board.

The WECAN Academy in July in Barcelona was one of my personal highlights. Seeing 100 people so enthusiastically participate in an extremely challenging four-day training programme on patient advocacy while also developing their networking skills was a real pleasure. It reaffirmed that the WECAN Academy is more necessary than ever.

We very much hope that these positive results will provide a good start to the new year, and I would like to express my heartfelt thanks to everyone. After 10 years of working as a network and now starting the year 2025 together with trustees and a new Management Board shows how strong the understanding is that we can only achieve the necessary changes by working together.

I wish you a healthy, joyful and peaceful 2025!



Anita Kienesberger

WECAN Chair

Childhood Cancer International Europe

Our Network



Leaders from pan-European cancer patient umbrella networks form WECAN. In 2024, WECAN's network consisted of 24 organisations representing 27+ disease areas. Each organisation is represented by one member and one alternate.

- Acute Leukemia Advocates Network
- Childhood Cancer International Europe
- CLL Advocates Network
- CML Advocates Network
- Digestive Cancers Europe
- EuropaDonna
- EuropaUomo
- EURORDIS - Rare Diseases Europe
- International Brain Tumour Alliance
- International Kidney Cancer Coalition
- MDS Alliance
- MPN Advocates Network
- Myeloma Patients Europe
- Melanoma Patients Network Europe
- International Neuroendocrine Cancer Alliance
- Lung Cancer Europe
- Lymphoma Coalition
- Pancreatic Cancer Europe Network
- Sarcoma Patients Advocacy Global Network
- Thyroid Cancer Alliance
- World Bladder Cancer Patient Coalition
- Youth Cancer Europe
- World Cancer of Unknown Primary Alliance
- Hereditary Cancer Advocates Europe

2020

WECAN expands its educational workstream with the first **WECAN Science** programme held in Brussels hosted by Melanoma Patients Network Europe. 26 participants and 10 faculty attend the two-day training event. A special training programme on **Evidence-Based Advocacy: Evidence Generation and Publications** is initiated as an online webinar series. The WECAN Academy, which was planned as an in-person event, shifts to virtual training series due to COVID. WECAN creates a **Virtual Meeting Resource Center** and COVID-19 resource page.

2021

WECAN Governance document is approved by all members. Due to the need for continued education, WECAN expands its educational offerings to an **eLearning platform** and launches the first open-access online course in **Patients in Publications**. WECAN responds to EU Parliament Hearings on Europe's **Beating Cancer Plan**. The first **LivingRoom Conversations** with WECAN is hosted to give WECAN members a place to connect and share experiences.

2022

The **European Atlas on Clinical Trials in Cancer and Hematology**, is launched. The eLearning platform expands with courses on **GDPR** and the **Fundamentals of Evidence-Based Advocacy**. The **EBA Strategy and Design Workshop** connects 8 advocates with EBA experts to launch research projects in 7 therapeutic areas. Through MPE, WECAN collaborates with PFMD on **Global Guidelines for Remunerating the Patient Community**. The network comes together to help Ukrainians in **Ukraine Crisis Coordination**.

2023

The **WECAN Governance document** was approved by all members. To strengthen the capacity and capabilities of patient advocates across the cancer patient community, WECAN **launched its WECAN Online Academy eLearning platform** and launched **open-access online training courses** on Patients in Publications, the EU Clinical Trials Regulation and GDPR. **WECAN responded to EU Parliament Hearings on Europe's Beating Cancer Plan**. WECAN hosted **LivingRoom Conversations** to give WECAN members a place to connect and share experiences.

2024

During the **WECAN April retreat**, members decided to establish a Foundation in the Netherlands after mindful explorations in order to choose the most suitable legal form. This decision marked a pivotal moment, with preparations completed by the end of the year. Additional highlights included the **January EBA Workshop**, and the **WECAN Academy**. Another key achievement was the launch of **PED courses**, an important initiative that provided participants with access to essential resources and training, made even more accessible through direct links.

WECAN Coordination Team & Legal Entity Workgroup 2024

The **WECAN Coordination Team**, composed of the Chair, Past Chair, WECAN coordinators, and other dedicated members, has played a vital role in ensuring smooth operations aligned with WECAN's mission and goals.

In 2025, with the establishment of the **WECAN Foundation**, this team will transition to the WECAN Management Board, led by the WECAN Management Board Director, with support from Anita Kienesberger as Past Director. While some 2024 team members will remain to ensure a stable transition, others are stepping back to make room for new voices to shape the Foundation's strategy. WECAN extends heartfelt gratitude to Hans Scheurer, Marzia Zambon, and Katie Rizvi for their invaluable contributions in 2024 and earlier years.

WECAN COORDINATION TEAM



Hans Scheurer
Myeloma Patients
Europe



Katie Rizvi
Youth Cancer
Europe



Marzia Zambon
EuropaDonna



Anita Kienesberger
WECAN Chair 2023 - 2024
Childhood Cancer International
Europe



Alex Filicevas
World Bladder Cancer
Patient Coalition



Gilly Spurrier
Melanoma Patients
Network Europe



Sara Dederichs
WECAN Secretariat/
European Patient
Advocacy Institute

We are delighted to announce that the **WECAN Legal Entity Workgroup** has reached a significant milestone: **submitting the statutes and operating rules!**

Formed in autumn 2023 by WECAN members, the group has worked tirelessly over many months, considering all input and ensuring the essence of WECAN as a non-legal entity is preserved within this new legal framework.

Huge thanks to the dedicated team – **Alfonso Aguaron, Anita Kienesberger, Ananda Plate, Gilly Spurrier, Hans Scheurer, Jacqueline Dubow, Jan Geissler, Mark MacDonnell, and Sara Dederichs** from the Secretariat, with **Francisco Mena** providing support as Legal Project Manager. This achievement marks an exciting step forward for WECAN!



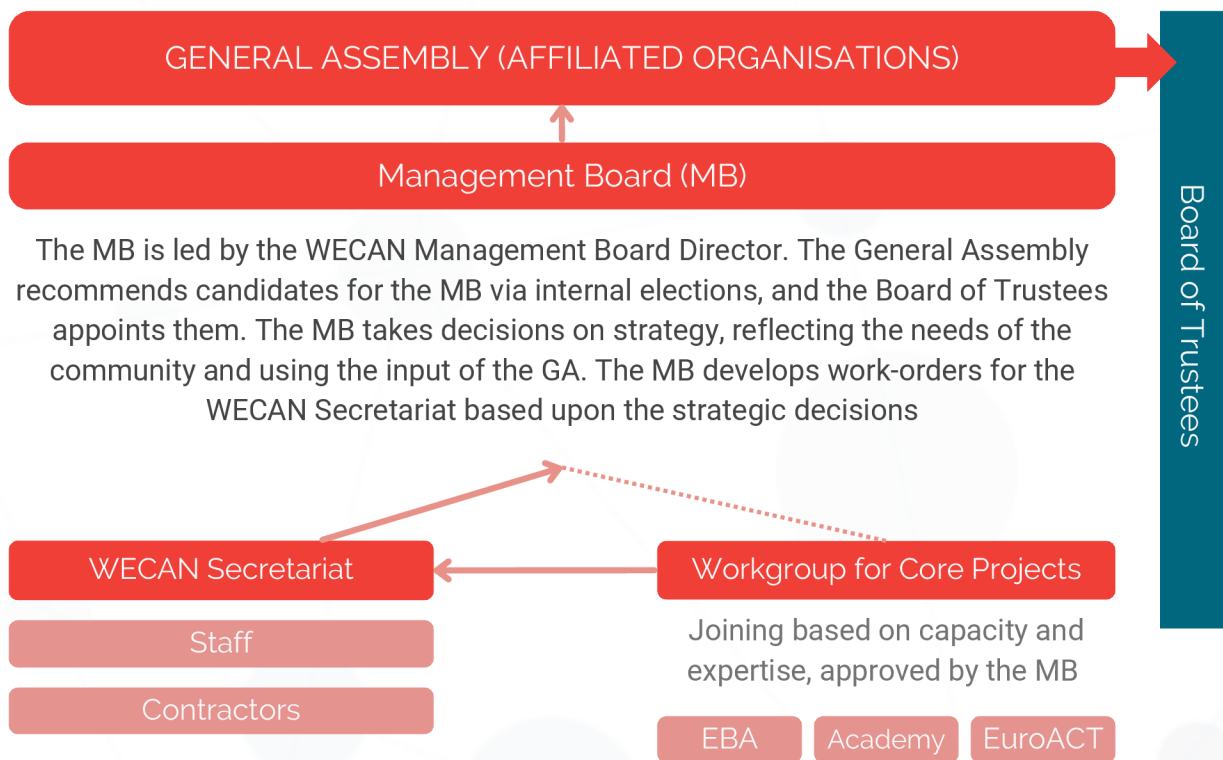
WECAN Foundation Governance

WECAN decided to establish itself as a Foundation to formalise operations, enhance credibility and ensure accountability. This structure fosters stakeholder trust, attracts funding and safeguards initiatives while enabling transparency and compliance with cross-border legal and financial requirements. The decision supports sustainability and aligns with the conversation's points on improving operational structure, ensuring trust and creating opportunities for partnerships and growth.

Each affiliated organisation of WECAN

- is an umbrella organisation
- is a non-profit
- is led by patients or carers

The formerly called Members of WECAN will be called affiliated Organisations of the new WECAN Foundation from 2025 on and will continue collaborating, learning and growing even stronger together.



The WECAN Foundation's governance ensures effective operations and accountability. The General Assembly represents the affiliated organisations, setting strategic priorities and electing leaders. The Board of Trustees (supervisory board) provides oversight and supports the mission of the organisation by ensuring compliance with legal and ethical standards. The Management Board handles daily operations, strategy implementation and resource management. The Secretariat supports operations, and Workgroups deliver project-specific outcomes.

WECAN Over the Years

Since 2015, WECAN has come together to collaborate and improve the outcomes for cancer patients in Europe.

2015

15 umbrella organisations come together to initiate WECAN out of the true need to work together as a community, avoid duplication of work, and collaborate.

2016

The **Guiding Principles on Reasonable Agreements between Patient Advocates and Pharmaceutical Companies** project is initiated.

2017

The **WECAN educational strategy** is created, initiating the WECAN Academy. WECAN begins to form its governance structure with the creation of the Governance Workgroup. Activities on understanding the patient community's perspective on **Fair Market Value** begin.

2018

The Guiding Principles are published. WECAN releases a **position paper** to further **EU integration of Health Technology Assessment**. WECAN launches a **survey on Fair Market Value**; 122 responses from patient advocates from 38 countries are received. Results are presented to Patients Focused Medicines Development and European Federation of Pharmaceutical Industries and Associations. WECAN pushes for patient representation on the Cancer Mission board. In education, WECAN joins the programme committee in the European School of Oncology's MasterClass in patient advocacy.

2019

The first **WECAN Academy** training programme is hosted in Frankfurt. Over 100 advocates attend the four-day training event that combined **WECAN SmartStart** and **WECAN Masterclass** programmes. Presentations are shared on the **WECAN Knowledge Base**. Myeloma Patients Europe leads the involvement of WECAN in **SISAQOL-IMI**

WECAN Foundation Management Board

The newly appointed WECAN Management Board brings a wealth of expertise and passion to lead the WECAN Foundation into its inaugural phase starting in January. The Management Board includes Alex Filicevas (World Bladder Cancer Patient Coalition), a leader in global cancer advocacy with extensive experience in healthcare consultancy and policy development; Anita Kienesberger (CCIEurope), a dedicated child cancer advocate renowned for cross-border collaborations and her involvement in WECAN's educational stream; Ariane Weinman (EURORDIS), a seasoned rare diseases advocate instrumental in EU patient-centric initiatives and European Reference Networks; Eric Briers (Europa Uomo), a champion for prostate cancer patients influencing clinical guidelines and policy; Gilly Spurrier-Bernard (MPNE), an experienced melanoma advocate with a focus on science and education; and Karin Kastrati (IKCC), a global advocate advancing kidney cancer collaboration and Mark Macdonnell, (INCA), a leader in neuroendocrine cancer advocacy and expert in fostering patient engagement in research. The Board of Trustees, made up of three distinguished individuals (voted by the WECAN members), will safeguard the Foundation's mission as a cancer patient community-led organisation. They will oversee the Management Board and Secretariat to ensure the Foundation operates legally and in alignment with its goals. The names of these three appointed individuals will be revealed in 2025.



Alex Filicevas



Anita Kienesberger



Ariane Weinman



Erik Briers



Gilly Spurrier



Karin Kastrati



Mark Macdonnell

In December 2024 the WECAN affiliated organisations voted a new Management Board for the upcoming WECAN Foundation.

This group of long-standing, highly experienced and committed advocates will work together from January 2025 in order to take strategic decisions, implement ideas coming from the WECAN Community, plan joint activities and safeguarding the Foundation's mission. The Director of this Board will be elected by the group in the first meeting in January.

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Past and Current Chairs



Geoff Henning

2018-2019
Digestive Cancers Europe



Ananda Plate

2019-2020
Myeloma Patients Europe



Gilly Spurrier

2020-2021
Melanoma Patients Network Europe



Jan Geißler

2021-2022
CML Advocates Network



Hans Scheurer

2022-2023
Myeloma Patients Europe



Anita Kienesberger

2023-2024
Childhood Cancer International Europe

Our Work with the European Patient Advocacy Institute

www.patientadvocacy.eu

The European Patient Advocacy Institute (EPAI) is a non-profit organisation that has been given the WECAN member's mandate to act as the administrative host for many WECAN projects.

EPAI was set up as a national spin-off from EUPATI. It has evolved as an international platform that hosts large evidence- and education-related advocacy initiatives and programmes for the cancer and hematology patient communities.

EPAI leads and guides the development and implementation of methodologies, processes, and projects to strengthen patient advocacy, patient involvement and evidence generation in research, health policy and healthcare services.



Role in WECAN

EPAI helps WECAN to achieve its mission to improve the outcomes for all cancer patients. EPAI currently runs the **WECAN Secretariat** and many of WECAN's programs and initiatives:

- WECAN Academy
- Evidence-Based Advocacy Programmes: Cancersurvey and PED (Patient Experience Data) Courses
- European Atlas on Clinical Trials in Cancer and Hematology (EuroACT)
- WECAN Knowledge Base

2024 PROGRAMMES AND INITIATIVES

WECAN had a banner year in 2024! Fueled by the passion of the WECAN network, the leadership of the WECAN Chair, and the tireless efforts of the Coordination Team, we tackled some of the most critical issues identified by the cancer patient community. With great support from our stakeholders, we focused on these key projects and initiatives:



WECAN Academy Face-to-Face 2024

For the 2024 edition, from **July 11th to 14th in Barcelona**, the program included the **WECAN Masterclass** and **WECAN SmartStart** sessions, catering to the educational needs of both novice and expert patient advocates. This year's event **retain the most valued activities and sessions from previous editions while introducing new ones** such as the *Panel discussion on AI, and Diversity, Equity, and Inclusion in Cancer Care*.

ESMO | All members meeting 2024

During **ESMO 2024**, a stakeholders' meeting shared updates on WECAN's initiatives, progress, and plans in education, advocacy, and organisational development. Key decisions, including **WECAN's establishment as a Foundation**, were discussed, and sponsors were updated on projects and future strategies.

Euro-ACT Dissemination of the project and results

In 2024, **EuroACT** was shared through a spotlight talk at EHA, a poster at ISPOR 2024, sponsor workshops, and a peer-reviewed manuscript submission, **promoting stakeholder engagement and methodological dissemination**.



Evidence-Based Advocacy

Evidence-Based Advocacy means advocating in a targeted, scientific, well-educated, and professional manner to drive change. For patient advocates to effectively advocate for unmet patient needs, they must generate robust data.

In 2024 we delivered the Evidence-Based Advocacy workshop and launched the first three modules of the Patient Experience Data Course (PED). This year, **alongside Module 4 and Module 5 which are part of the PED Course, we will be launching the Cancersurvey** (see p.18 for more info).



Cancersurvey represents a collaborative effort among the WECAN member organisations to explore cancer patient and survivor experiences (from the moment of diagnosis, tracking treatment, care, quality of care, communication, support and life post-treatment). The data generated in this project will help guide future advocacy projects, provide insights into the next research priorities and assist in better understanding how to support patients, survivors and carers. Furthermore, we are excited to share that in 2024, some of the Evidence-Based Advocacy courses were translated and delivered to cancer patient organisations in **Japan**, while the **Patient Experience Data course** was launched. In 2025, all 5 modules of the latter will be available on the WECAN Academy online learning platform as a open source learning opportunity.

<https://academy.wecanadvocate.eu/>



Education

One of WECAN's key objectives is to increase the capacity and number of well-trained patient advocates in order to further grow a community of activists that can induce change. WECAN educates patient advocates on the three knowledge pillars:



**Advocacy
Tools and Skills**



**Healthcare Systems,
Policy and Access**



**Research
and Data**



The WECAN Academy is a comprehensive training program designed to empower patient advocates of all levels -from novice to expert- by enhancing their understanding and skills across various areas of advocacy. Originating as a four-day training event in 2019, the WECAN Academy has evolved to encompass a virtual training series and on-demand courses, ensuring accessibility and flexibility for participants.

In 2024, we celebrated a successful milestone with the WECAN Academy held in Barcelona from 11th-14th July, where we welcomed a **record-breaking attendance of 100 patient advocates** from diverse backgrounds, countries, and disease areas. The Academy featured **more than 25 sessions and over 15 speakers**, offering targeted training through two distinct tracks: SmartStart for patient advocate trainees and MasterClass for experienced advocates. With three key knowledge

pillars -Advocacy Tools and Skills, Healthcare Systems, Policy and Access, and Research and Data- the event continued to highlight WECAN's commitment to strengthening the advocacy community.



ONLINE LEARNING PLATFORM

Capacity-building programs in patient advocacy

WECAN's educational platform includes several free open access courses:

- Fundamentals of Evidence-Based Advocacy
- GDPR for Patient Organisations
- Patients in Publications
- Understanding the EU Clinical Trial Regulation no. 536/2014

From 2023 and in 2024, WECAN developed on-demand educational modules to meet the needs of patient advocates across Europe and beyond, and a new course on Patient Experience Data was launched.



Available Courses on

Academy.wecanadvocate.eu

WECAN's Evidence-Based Advocacy Program in Japan

In 2023, WECAN was contacted by **PanCAN Japan**, an organisation dedicated to fighting pancreatic cancer, to deliver a brief presentation on Evidence-Based Advocacy Basics. The presentation, which lasted 30 minutes, was successfully delivered in 2024 and is currently being translated into Japanese for distribution to PanCAN members.

Patient Experience Data Course

In the first three modules of this course, aspiring and seasoned patient advocates delve into the definitions and roles of **Patient Experience Data (PED)**, and its aim in improving health outcomes and enhancing care quality. Participants gain a comprehensive understanding of different types of PED, including Patient Preference, Patient-Reported Outcomes, and Real-World Evidence, as well as the methodologies for collecting both quantitative and qualitative PED. The course also explores the integral role of PED in regulatory reviews and clinical trial design, highlighting the significance of patient engagement throughout the entire medical product development process.

In **module 4**, experts from patient organisations (POs) present real-world case studies to further illustrate these concepts and enable patient advocates to take active part in PED research and evidence-based advocacy.

NEW

PATIENT EXPERIENCE DATA / MODULE 5

Module 5 is a pilot program developed through collaboration among **IQVIA, the European Patient Advocacy Institute, WECAN, EUPATI, and ECHAlliance**. It aims to empower patient organisations as data cooperatives and fiduciaries, placing them at the forefront of data collection, management, governance, ownership, and security. In this course, participants will gain knowledge about developing data strategies and business models for POs. Key topics include the data landscape, stakeholder interests, policies on data processing, protection, governance, and common standards. By the end of the module, which will be launched in 2025, participants will understand the role of POs in data management and explore potential funding and income models related to data generation and analysis.

WECAN's Evidence-Based Advocacy Programme

WECAN's educational initiatives focus on Evidence-Based Advocacy (EBA), emphasising the importance of advocating in a scientific, targeted, and professional manner while measuring advocacy impact.

Recognising the increased awareness and importance of EBA within the patient community, WECAN addresses the educational gap by providing training on how to generate and utilise data in advocacy.

Since 2020, WECAN has trained advocates to conduct evidence-generation projects and publish their findings. Recently, in early 2024, WECAN conducted a workshop attended by over 40 participants, including patient advocate trainees, experts, clinicians, industry stakeholders, and researchers.

The workshop aimed to equip participants with essential skills to develop evidence-generation projects, focusing on identifying unmet needs of cancer patients, refining research methodologies, and crafting effective communication strategies.

This workshop laid the groundwork for the WECAN Cancersurvey project, representing a collaborative effort to gather insights into patient experiences. All interested trainees and WECAN members now have the opportunity to collaborate, to further enhance the strategy for the Cancersurvey.

Main topic areas identified where additional data needs to be collected for targeted advocacy actions:

- HEALTH SYSTEM CAPACITY
- MANAGEMENT OF CHRONIC DISEASES
- PATIENT ORGANISATIONS SUPPORT
- MENTAL HEALTH
- SHARED DECISION-MAKING
- FINANCIAL TOXICITY
- LONG-TERM FOLLOW-UP
- END-OF-LIFE AND PALLIATIVE CARE FOR CANCER PATIENTS



It provided a fantastic overview of so many different types of patient experience data. I would highly recommend for anyone intending to design and conduct a survey, collect data or do any advocacy project.

High quality and relevant information provided by excellent speakers. I gained many new skills, mindsets and understandings.



17-19th Jan 2024



Munich



40 Participants



20 Countries

Research

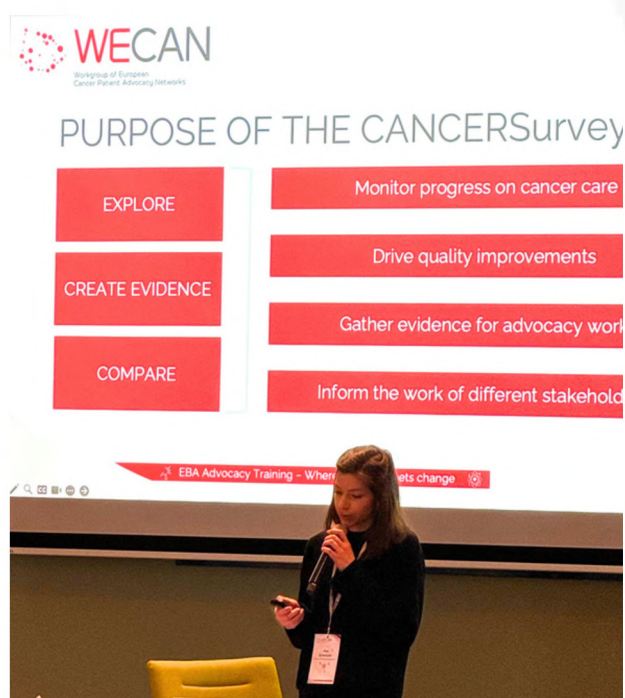
WECAN believes in targeted advocacy towards each stakeholder through the use of robust data to communicate patient needs effectively.

CANCERSurvey

Following the face-to-face Workshop in Munich in January 2024, WECAN initiated a collaborative effort to develop the **CANCERSurvey**, a project that aims to understand cancer patient and survivor experiences across major cancer types.

The **CANCERSurvey** is a cross-sectional pan-European survey study aiming to gather and compare **Patient Experience Data (PED)** on cancer patient journey, from the moment of diagnosis to treatment, care, quality of care, communication, support, and life post-treatment, and results publication across multiple disease areas in cancer.

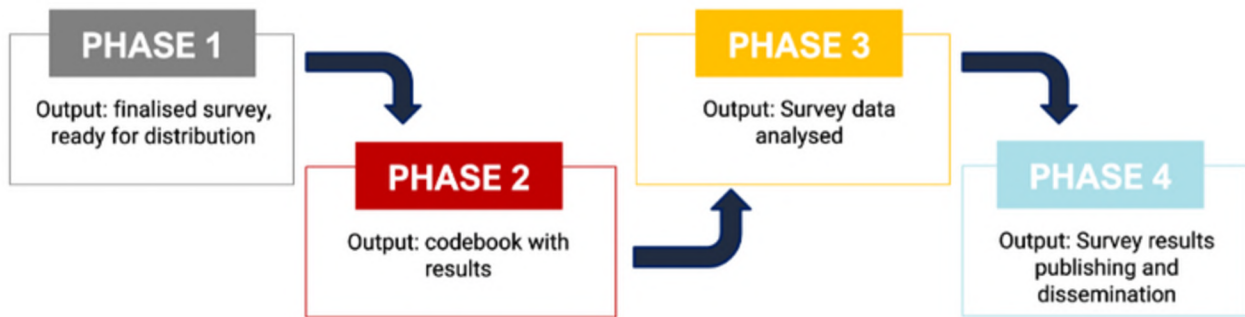
Studies point out that without providing patients with an optimal experience, their health and well-being cannot be enhanced. As a result, PED has become prevalent in drug development and regulatory processes, as it can guide decisions in research and clinical practices during intervention creation and commercialisation.



Research

However, while PED is collected among various cancer types, **there is a lack of consistent and standardised measures, making patient experiences comparison across cancer types ineffective.** This, in turn, leads to an inability of identifying best practices of care and equitable care provision across different cancer types, and to healthcare policies and treatment approaches that do not necessarily meet patients' needs.

The Cancersurvey is divided in 4 Phases and its objectives include developing community and disease-specific insights for advocacy purposes, collaboration on the project and involving representatives from WECAN member organisations in the survey development process.



Updates & Next Steps

In 2024, the Cancersurvey kicked off and WECAN is preparing to involve its members in the development of the survey. Once Phase 1 is completed, the survey will be distributed across Europe, and the resulting data will be used to equip cancer patient organisations with tools to address key priorities within their disease areas and across the broader community.

Solid evidence will enable meaningful stakeholder dialogue. Additionally, support will be offered to organisations needing to promote effective use of the evidence, enhance project outcomes, share insights, avoid resource duplication, and empower community members to achieve meaningful advocacy impact.

EuroACT: Turning data into evidence for advocacy

The generation of evidence is the focus of the European Atlas on Clinical Trials in Cancer and Hematology (EuroACT) project. EuroACT focuses on **addressing inequalities in access to clinical trials across Europe and improving the use of Patient-Reported Outcomes (PROs) and Health-Related Quality of Life (HRQoL) measures**. The project aims to understand disparities in trial availability, evaluate the collection and publication of PRO data, and identify gaps in research. By analysing trends over five years, EuroACT seeks to enhance patient-centred care, guide policy reforms and develop evidence-based recommendations for advocacy.



EuroACT European Atlas on Clinical Trials in Cancer & Hematology

WECAN **EuroACT** **syreon**
Research Institute

European Atlas on Clinical Trials in Cancer and Hematology (EuroACT): Patient Access Disparities and Underuse of Patient Reported Outcome Measures

Cases M, Imre A, Giles R, Ruth L, Piggion M, Geisler J, Agh T, Hosszu D, Jozwiak-Hagymasy J, Jozwiak A, Plate A

PCR111

INTRODUCTION
Patient communities have long expressed concerns about limited access to clinical trials in cancer, hematology as well as the inconsistent use and reporting of patient-reported outcome measures (PROMs) [1] With inconsistent adherence to reporting standards and variability in patient-reported outcomes (PROs) usage and collection methods, highlighting the need for standardized protocols to improve the reliability and the impact of PROs in oncology research [2]

OBJECTIVES

- The primary objective of EuroACT is to comprehensively analyze the landscape of clinical trials in the European region encompassing 27 disease areas in oncology and hematology.
- This analysis focuses on three main aspects: geographical distribution of clinical trial sites across Europe, extent to which PROs are collected in clinical trials, and publication rates of PRO data gathered during trials.

METHODS

- Predefined searches were conducted on EU EudRACT, the US ClinicalTrials, and other datasets to compile a fit-for-purpose database on interventional and observational trials.
- Only trials completed between 2017-2022 were included, which investigated at least one of the 27 disease areas registered in at least one European country (as defined by WHO) and excluding Phase I studies.
- PROs were identified based on preliminary literature search and publication data derived from PubMed.

RESULTS

- Analysis of 5,171 completed trials revealed substantial geographical disparities: Western Europe hosted the highest proportion of trials (73.4%), followed by Central and Eastern Europe (13%), Southern Europe (54.5%) and Northern Europe (31.4%).
- Only 19% of trials incorporated PROMs.
- The most frequently used PROMs were the EORTC-QLQ-C30, EQ-5D and SF-36.
- Fewer than 1% of trials had associated publications on PubMed, out of which only a few trials included PRO data.

CONCLUSION

- Significant geographical disparities in access to oncology and hematology clinical trials create substantial barriers to innovative treatments across various regions in Europe.
- Publication of trial results is inconsistent and can contribute to patient mistrust in the clinical trial landscape.
- Only a subset of trials incorporated PRO measures, and their data is infrequently published.
- Collectively, this analysis highlights a critical gap in capturing the patient voice, which is indispensable for improving treatment strategies.

REFERENCES

1. George, S. H., Williams, J., Anderson, M., et al. (2021). Trust and current practice of patient-reported outcome measurement in oncological cancer clinical trials: a systematic review. *Value in Health*, 24, 889-901.
2. S. Bjork, M. K. G. J. J. et al. (2018) Post-patient-reported outcomes reporting according to CONSORT guidelines in randomized clinical trials evaluating systemic cancer therapy. *Annals of Oncology*, 29, 211-217

Presented at the ISPOR Europe 2024 Conference, 17 - 20 NOVEMBER 2024, BARCELONA, SPAIN

Scan the QR codes to visit the websites

WECAN **EuroACT** **Syreon**

Dashboards

NAME	STATUS	TAG	OWNER	PROJID
EuroAct #07 Evaluating the nature of outcomes assessed by PROMs in clinical trials across disease areas	Published			
EuroAct #11 Characterizing publications reporting PROM data from clinical trials across disease areas	Published			
EuroAct #10 Exploring the influencing effect of clinical trial characteristics on the publication rate of PROMs in clinical trials...	Published			
EuroAct #08 Characterizing PROMs utilized in clinical trials across disease areas	Published			
EuroAct #05 Geographic variability in PROMs utilization in clinical trials across disease areas	Published			
EuroAct #03 Assessing the impact of study population age group on the country differences in clinical trial activities across...	Published			
EuroAct #01 Investigating regional and country differences in clinical trial activities across disease areas	Published			
EuroAct #04 Analyzing the influence of study sponsor type on the regional and country differences in clinical trial activities...	Published			
EuroAct #02 Exploring the influence of socioeconomic and scientific factors on the country differences in clinical trial activi...	Published			
EuroAct #09 Investigating the publication rate of PROMs in clinical trials across disease areas	Published			
EuroAct #06 Investigating the influencing factors of PROMs usage in clinical trials across disease areas	Published			
EuroAct #00 Introduction	Published			



EuroACT

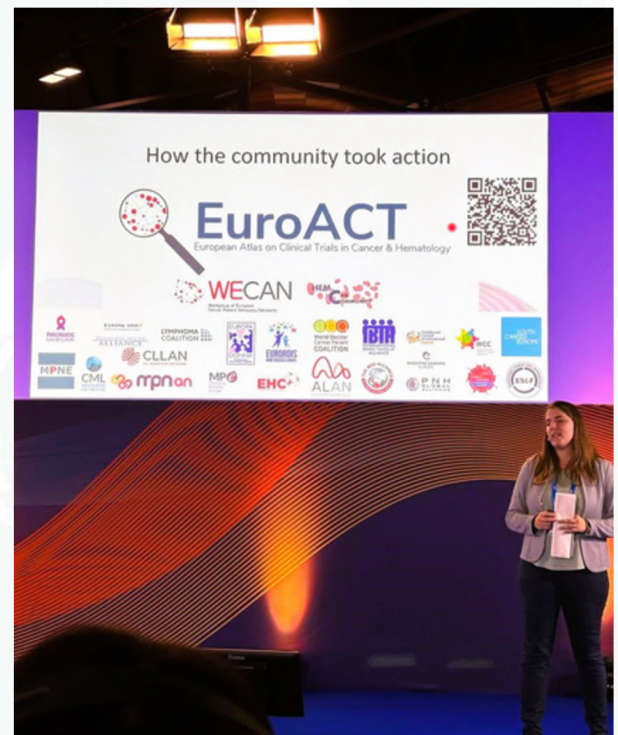


Access to clinical trials is a pressing issue for European patient organisations, particularly those representing individuals with life-threatening and rare hematological diseases. Beyond providing access to innovative therapies, the presence of clinical trials in a patient's home country increases the likelihood of new treatments becoming available locally. Unfortunately, many clinical trials are concentrated in a limited number of European countries, leaving others, particularly in the Central and Eastern European (CEE) region, underserved.

This **disparity** not only limits patient access but also leads to the migration of researchers and clinicians seeking better opportunities, further weakening healthcare systems in neglected regions. Moreover, the absence of local trials can hinder medicine approval and reimbursement, as treatments tested locally are more likely to gain acceptance by national bodies.

In addition, a significant challenge is that **many clinical trials fail understanding how treatments affect patients' daily lives, well-being, and symptoms**, underscoring the need to analyse Patient-Reported Outcomes (**PROs**) and Patient-Reported Outcome Measures (**PROMs**) to address their priorities.

Without this data, trials miss an essential perspective, leading to an incomplete understanding of the real-world value and impact of therapies on patients, thereby limiting patient-centred care and decision-making.



The EuroACT project ("European Atlas on Clinical Trials in Cancer & Hematology") analyses access to clinical trials and how treatments impact patients in Europe. The aim is to gather evidence to promote more patient-centred care and decision-making.

This initiative involves **27 pan-European organisations** and seeks to **generate evidence** for meaningful reforms while driving policy action to ensure equitable access and robust quality-of-life assessments in future clinical trials.



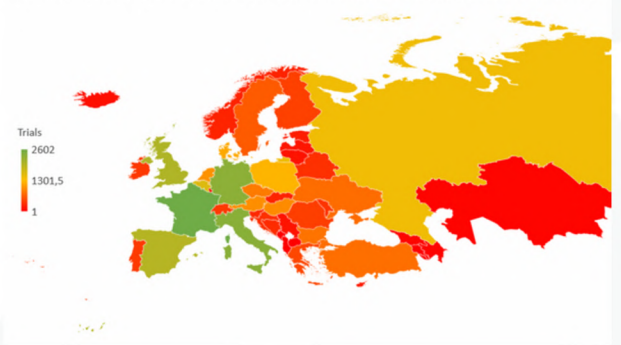
The EuroACT project focuses on: 1) Mapping the clinical trial landscape across Europe and 2) Evaluating the inclusion of Patient-Reported Outcomes (PRO) and Health-Related Quality of Life (HRQoL) measures. 3) Assessing the publication of PRO data.

Throughout 2024, the EuroACT project has focused on analysing the extensive data gathered in Phase 1. The Steering Committee and WECAN members collaboratively established key research questions during the WECAN retreat in Barcelona, aligning the analysis with the community's priorities.

With these questions guiding the process, the analysis delved into all variables captured during Phase 1, aiming to uncover critical insights about clinical trial disparities and the use of Patient-Reported Outcomes (PRO) and Health-Related Quality of Life (HRQoL) measures. Simultaneously, an **interactive dashboard** was developed to visualise and disseminate the findings, enhancing accessibility and utility for stakeholders.

By July 2024, preliminary insights were reviewed during a steering committee meeting, followed by a sponsor workshop at **ESMO 2024**, where key findings and dashboard applications were discussed.

Number of clinical trials across countries for all disease areas combined

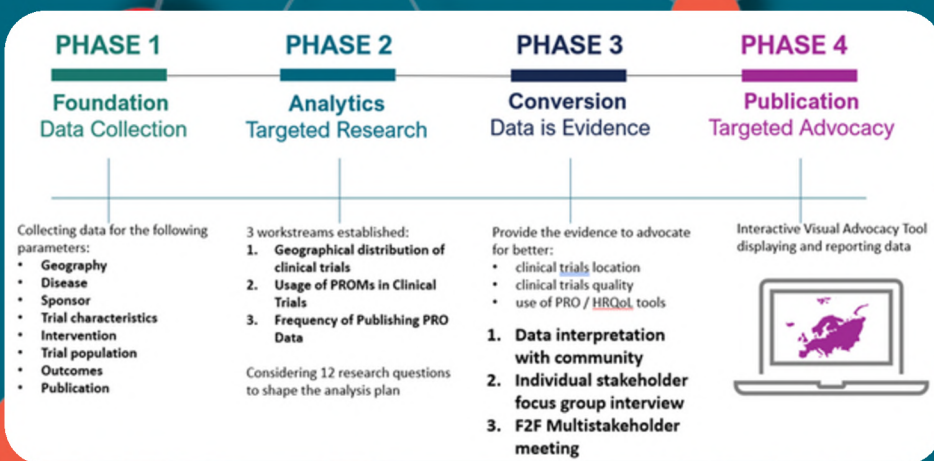


Dissemination efforts included a spotlight talk on PRO usage at **EHA 2024 in Madrid** and a poster presentation on patient access disparities at **ISPOR 2024** in Barcelona. By the end of 2024, both the comprehensive analysis and the interactive dashboard were finalised, marking a significant milestone in the project.

In collaboration with Syreon, we developed a **novel methodology** specifically designed to collect and analyse data for EuroACT. This innovative approach was essential to achieving our project goals. A major milestone of this effort was the **submission of an open-access, peer-reviewed manuscript in 2024**, detailing the methodology used in the project.

The manuscript aims to:

1. Clearly demonstrate the reliability of this new method to researchers in the field and invite constructive feedback.
2. Enhance the project's visibility by providing an openly accessible document that can reach diverse audiences.
3. Encourage researchers and patient advocacy groups to apply this methodology to other disease areas. This publication highlights the ground-breaking nature of our work and its potential to benefit a wider community.



Next steps: Looking ahead to 2025

In 2025, the project will advance to **Phases 3 and 4**, focusing on evidence generation and advocacy. Building on Phase 2 outcomes, a multistakeholder approach will guide evidence synthesis. Input will be collected from patient organisations, industry representatives, clinicians, PRO experts, regulatory bodies and HTA experts, culminating in a consensus-building meeting to align diverse perspectives.

This process aims to ensure that findings are actionable and reflective of stakeholder priorities. Simultaneously, efforts will focus on publishing the project outcomes and refining the interactive dashboard for public access. The dashboard will serve as an open-access tool, providing valuable insights into clinical trial disparities and the integration of PRO/HRQoL measures, ultimately driving awareness and policy action.



For more information about WECAN and EuroACT, visit the link <https://wecanadvocate.eu/projects-and-initiatives/euroact/> or scan the QR Code above.

Members News & Activities

WECAN's member organisations had a memorable 2024 engaged in several initiatives in support of cancer patient communities and patient advocacy.

Here are some of the highlights from our members' activities and engagements throughout the year.



Throughout 2024, WECAN members presented WECAN's initiatives and activities in many key international and European meetings and conferences or attended them on behalf of WECAN's mission.

WECAN engagements in 2024

- ASCO
- ASH
- Cancer Mission
- CDDF
- CraNE
- DIA Europe
- EFPIA
- EHA
- ESMO
- EUPATI AGM
- European Cancer Summit
- Europe's BeatingCancer Plan
- EU Parliament Event
- ISPOR 2024
- Patient Engagement Open Forum
- PFMD

We thank all WECAN members for their important contributions to those meetings.

Members News & Activities

WECAN is proud to share the many significant accomplishments from the cancer patient advocacy community in 2024. Throughout the year, WECAN member organisations have made substantial strides in advancing patient advocacy, achieving important milestones that have helped improve the lives of cancer patients across Europe



WECAN Retreat 2024 in Barcelona 22 of 24 members organisations attending



ALAN - Acute Leukemia Advocates Network



The Acute Leukemia Advocates Network (ALAN) is a global patient-led group advancing advocacy, awareness, education, and collaboration to improve outcomes for **acute leukemia** patients and carers worldwide.

In 2024, ALAN made significant strides in advocacy, education, awareness, and research for acute leukemia patients and carers.

The **network expanded** to 59 members across 53 countries and strengthened its digital presence, with notable growth on social media and the addition of a clinical trial finder.



ALAN - Acute Leukemia Advocates Network

Key awareness initiatives included the **#BeLeukemiaAware** campaign, **World Leukemia Day**, and **Blood Cancer Awareness Month**, promoting early detection and patient empowerment. Education efforts featured webinars on health technology assessments (HTAs) and updates on leukemia treatments. Regional virtual meetings were held for Europe, LATAM, and North America to foster collaboration and support advocacy development.

ALAN prioritised **evidence-based advocacy** by conducting global patient and carer experience surveys and patient preference studies, generating crucial insights on quality of life and treatment impacts.

EHA2024
JUNE 13 - 16 | MADRID

DISEASE AND TREATMENT BURDEN IN PATIENTS WITH LEUKEMIA: FAMILY MEMBERS/PARTNER PERSPECTIVE

INTRODUCTION
It is recognized that patients with leukemia require treatment, hospital admission and care, financial support and support provided by family members/partners. The impact of leukemia on family members can be profound and multifaceted, affecting emotional, physical, financial, and social aspects of life. An increased awareness of these aspects is needed to better identify areas of support.

AIMS
The global network partnership of Acute Leukemia Advocates Network (ALAN), Chronic Myeloid Leukemia (CLL) Advocates Network (CLAN) and the Chronic Myeloid Leukemia (CMO) Advocates Network (COMO) aims to raise the network's awareness of a multi-country study aimed to assess the burden of leukemia on patients and on their family members/partners. The aim of the study is to assess the burden of leukemia on patients and on their family members/partners. The aim of the study is to assess the burden of leukemia on patients and on their family members/partners.

METHODS
A global experience online survey was conducted from 18 September 2023 to 30 October 2023 to investigate the experience of patients with leukemia and family members/partners. The questionnaire consisted of 44 questions (34 on the quality of life and 10 on the burden of leukemia on family members/partners). The questionnaire was distributed to patients with leukemia and family members/partners via email and social media. The questionnaire was distributed to patients with leukemia and family members/partners via email and social media.

RESULTS
Characteristics of family members/partners
Overall, 571 family members/partners responded to the survey.
Table 1. Main characteristics of family members/partners

Characteristic	n (%)
Age (years)	55.2 (14.5)
Gender	162 (28.4)
Female	405 (71.6)
Not specified	9 (2.0)
Relationship with patient	328 (57.4)
Partner or partner	102 (17.9)
Spouse or partner	36 (6.3)
Other	18 (3.2)
Family member/partner employment (n=564/98%)	
Employed	338 (60.1)
Unemployed	105 (18.5)
Student	10 (1.7)
Retiree/over 65	11 (2.0)
Not specified	28 (5.0)

Activities
106 (18.6%) family members/partners did not understand the diagnosis. According to 86 of 207 (41.6%) family members/partners with the patient at the site in which the diagnosis was confirmed, it should have been done more quickly.

Experience with information received
Family members of the 404 (70.7%) who decided to attend the program, 104 (25.7%) received information from the program and 17 (4.2%) family members who did not decide to receive such information.

Perception of patient's quality of life
However, the impact of disease on patients was underestimated by family members/partners as reflected by the fact that 78.4% of those completed by the family members who provided the form listed other perceptions of the patients (see Figure 1).

CONCLUSIONS
The burden of leukemia on family members/partners is often underestimated, despite the high level of patient experience when attending to provide family care. The study indicates that it is important to have a better understanding of the burden of leukemia on family members/partners and how this impact should be properly recognized when developing or providing information and care and emotional support services.

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DISCLOSURES AND ACKNOWLEDGEMENTS
All authors contributed to and approved the presentation. The authors would like to thank the patients and families who made the study possible. Financial support was provided by AstraZeneca (AZ), MSD, and Novartis. Clinical assistance was provided by Core Sight (AZ Medical Writing 2023), PMA, and Novartis.

The findings were presented at the **European Hematology Association (EHA) Congress**, in June 13-16, Madrid, where ALAN showcased posters, including **“Disease and Treatment Burden in Patients with Leukemia: Family Members/Partner Perspective.”**

ALAN also supported local projects in Spain, Tanzania, Guatemala, and South Africa, focusing on awareness, mental health and community engagement. By collaborating with organisations like the European Hematology Association and leading initiatives like **CARTALLEU**, ALAN continues to champion improved care, advocacy, and research for the leukemia community.



CCI Europe - Childhood Cancer International Europe

During 2024, **Childhood Cancer International Europe (CCI Europe)** has taken significant steps to advocate for better care, research, and policy initiatives for childhood cancer through several key efforts:



The CCI Europe and SIOPE Manifesto

Ahead of the 2024 European elections, CCI Europe and SIOPE launched a manifesto outlining key policy asks and recommendations for the 2024-2029 mandate. Over 90 MEPs and 40 organisations have endorsed the manifesto, pushing for equal access to care and research to improve survival and quality of life.

Publications

CCI Europe has published three papers recently. "Patients', Parents', and Survivors' Perspective about AI Applications in Paediatric Oncology," delves into the views of patients, parents and survivors regarding the application of artificial intelligence (AI) in paediatric oncology. Moreover, CCI Europe organised and led the outcomes of two multi-stakeholder workshops, during which there was a deliberation on the complexities, ethical considerations and moral dilemma of randomized clinical trials (RCTs) in paediatric oncology. Lastly, the workshop report "Asking those who know their needs best: A framework for active engagement and involvement of childhood cancer survivors and parents in the process of psychosocial research – A workshop report" focuses on developing methods to engage childhood cancer survivors and caregivers in shaping research.

The Children's Rights Day Event

On November 19, SIOPE Europe and CCI Europe hosted a policy event at the European Parliament in Brussels to spotlight challenges the childhood cancer community faces in Europe, under frameworks like Europe's Beating Cancer Plan, focusing on access to cross-border health care and research.





DiCE- Digestive Cancers Europe

On November 14 and 15, **Digestive Cancers Europe (DiCE)** and EuropaColon Portugal proudly hosted **ENTERO2024** in the scenic city of Porto, Portugal.

This groundbreaking conference, co-funded by the European Union, brought together patients, healthcare providers, researchers, and policymakers to address one of oncology's fastest-growing challenges: early-age onset digestive cancers.

Over two days, ENTERO2024 delivered a dynamic program of patient testimonials, scientific updates, and forward-looking discussions to improve diagnosis, treatment, and survivorship outcomes.

The impressive line-up of speakers shared actionable insights, emphasising the need for earlier diagnoses, tailored treatments, and increased research into lifestyle and environmental factors. Discussions underscored a clear message: every patient deserves timely, personalised care.

ENTERO 2024 reinforced a shared mission to improve the outlook for young-onset digestive cancers, inspiring partnerships and solutions that meet patients' unique needs during this critical time in their lives.

[Learn more about ENTERO2024](#)



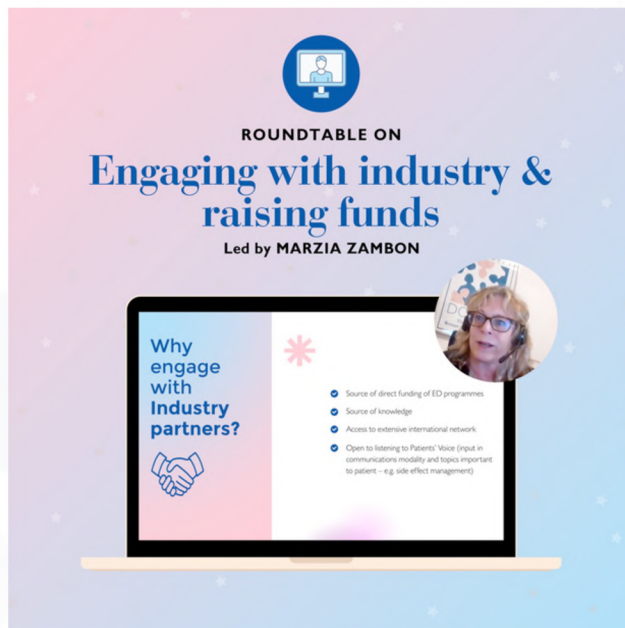


Europa Donna

2024 was an **important year for Europa Donna as we celebrated 30 years of advocacy!** The festivities began from 20-22 March in Milan at the 14th **European Breast Cancer Conference (EBCC14)**, co-organised by Europa Donna together with EUSOMA and the EORTC. Attended by 1,800 participants from 74 countries, the conference focused on metastatic breast cancer through the EBCC14 Manifesto, which called for greater visibility, better data collection, and improved access to innovation for MBC patients. Directly following the conference, we hosted an intensive day-long, in-person educational event for Europa Donna members, providing a layman-friendly overview of key advocacy messages from EBCC14 and other current issues.

On 15th October, Europa Donna marked **Breast Health Day** by encouraging breast cancer prevention and early detection, promoting a healthy lifestyle with balanced diets, regular exercise, limited alcohol, avoiding smoking, and routine check-ups.

Europa Donna's **Advocacy Leader Conference**, held on 16th November in Milan, brought together 70 experienced advocates for a day of learning, skill-building, and sharing expert insights. Throughout the year, Europa Donna also reinforced its commitment to improving breast cancer outcomes with **several roundtables and an MBC webinar**. The coalition remains dedicated to driving meaningful change for breast cancer patients across Europe.



Europa Uomo is a European **prostate cancer** advocacy organisation dedicated to raising awareness, promoting early detection, and improving the quality of life for patients and their families.

It operates on three pillars—**raising awareness, promoting early detection, and advocating for treatment** in specialised cancer centres. It actively supports the implementation of the EU Beating Cancer Plan recommendations for prostate cancer screening through the PRAISE-U initiative.

In 2023/24, its efforts centred on strategic initiatives, impactful projects, education, and advocacy: Key projects included the **EUPROMS 2.0 survey**, which assessed the quality of life for 3,600 prostate cancer patients, and the **EU-ProPER study**, which evaluated the burden on partners, gathering over 1,100 responses. The organisation also partnered in the **DE-ESCALATE** trial to explore innovative treatment approaches for metastatic hormone-sensitive prostate cancer.

To enhance education and advocacy, Europa Uomo launched its first **Summer School**, offering advocacy training and updates on medical advancements, and organised webinars focusing on active surveillance for low-risk prostate cancer patients. Its communication efforts resulted in a 33% increase in website traffic, and new resources, such as a chatbot for prostate cancer queries, are planned.

Europa Uomo **expanded its membership and strengthened partnerships** with new organisations, while maintaining transparent financial management. The organisation continues to play a pivotal role in implementing the EU Beating Cancer Plan through initiatives like PRAISE-U, fostering early detection and cost-effective screening across Europe. These efforts highlight Europa Uomo’s dedication to improving prostate cancer outcomes through collaboration, research, and advocacy.





IBTA - International Brain Tumor Alliance

In 2024, the **International Brain Tumour Alliance (IBTA – www.theibta.org)** continued its work as a global leader in patient advocacy through impactful publications, policy work, and international collaborations. These initiatives continue to highlight the unmet needs of brain tumour patients and their caregivers while fostering innovation and solidarity across the community.

Over the last twelve months, the IBTA published its **Report of the Fifth Biennial World Summit of Brain Tumour Patient Advocates** (<https://theibta.org/ibta-news/report-on-5th-world-summit-of-brain-tumour-patient-advocates-published/>).

Held in Vienna in 2023, the Summit emphasised the deeply personal journey of brain tumour patients and families. Participants advocated for timely diagnoses, expanded treatment options, effective therapies, and robust psychosocial support to address the multifaceted impact of brain tumours.

Additionally, the IBTA in collaboration with the **American Brain Tumor Association, organised a Symposium (2023)** (<https://theibta.org/ibta-news/international-patient-advocacy-symposium-on-brain-metastases-report-now-available/>) in Vienna for leaders of major patient advocacy organisations from the fields of melanoma and breast, lung, brain and kidney cancers, to discuss the unmet needs of the metastatic brain tumour community. The Symposium ultimately led to the creation in 2024 of the Brain Metastases International Collaborative.

The IBTA also released the latest edition of its flagship **Brain Tumour Magazine** (www.theibta.org), a 132-page publication with 10,000 copies for distribution in over 100 countries. It features diverse perspectives, patient stories, treatment updates, and policy discussions, fostering global collaboration and awareness.

Finally, an IBTA-led, 2024 paper, **“Brain tumour patients’ rights and the power of patient advocacy: the current international landscape”** (Editor’s Choice in Neuro-Oncology Practice, <https://doi.org/10.1093/nop/npae079>) addresses unmet needs in brain tumour care within the framework of “The Brain Tumour Patients’ Charter of Rights”.



INCA- International Neuroendocrine Cancer Alliance

The **International Neuroendocrine Cancer Alliance (INCA)** achieved significant milestones in 2024, enhancing awareness of neuroendocrine cancer (NENs) and empowering patient advocacy.

Think NENs Global Educational Program for Primary Care Physicians

In October, INCA launched a free, CME-accredited e-learning program tailored for primary care physicians. This initiative equips physicians with concise knowledge on NEN diagnosis and management through a 60-minute educational module and 13 supplementary videos. Available in six languages, the program was developed with input from global NEN experts, patient representatives, and primary care physicians. It has certified trainees from Italy, Mexico, the UK, and India and was showcased at major medical conferences.

NET Cancer Day 2024

On November 10th, INCA united the global NET community with the message, “Easily missed. Take a closer look at neuroendocrine cancer.”

Resources, including multilingual campaign materials and patient stories, emphasised the Think NENs program. A social media campaign in 11 languages reached 14.1 million people, with 26 thousand new website visitors in 20 days.

Advancing Advocacy and Awareness

The 12th INCA Global NET Patient Advocate Summit in Spain brought together over 30 representatives to discuss improving diagnostics, care, and patient-driven research. Advocacy efforts included new video resources, multilingual factsheets, and collaborations with medical experts. INCA leaders highlighted patient perspectives at seven international conferences



Discover more about INCA's 2024 initiatives:

- Think NENs Program: <https://incalliance.org/think-nens/>
- NET Cancer Day: <https://incalliance.org/net-cancer-day-2024-around-the-globe/>
- 2024 Review Video: <https://youtu.be/VkGd78u-LNI>



LuCE - Lung Cancer Europe

In November 2024, Lung Cancer Europe (LuCE) published its 9th Report, "Empowering voices: Knowledge and decision-making among people impacted by lung cancer in Europe." This comprehensive research explores the level of information, knowledge and decision-making involvement among those affected by lung cancer in Europe, from data collected through a six-week survey completed by 2,040 participants (1,432 patients and 608 caregivers) from 34 WHO European Region countries.

Among its key findings, the research revealed that while 98% of patients believe their opinions should be considered in treatment decisions, only half reported being highly involved in the decision-making process. Additionally, although 89.2% of participants considered information extremely important, 40.2% did not receive enough information and nearly one-third struggled to understand the information provided.



The LuCE Report is a comprehensive pan-European research initiative that has established itself as a significant evidence-based document addressing key themes affecting people impacted by lung cancer across Europe.

Published yearly, each edition focuses on a chosen priority, with participation growing significantly year on year, and serving as a crucial tool for lung cancer patient advocacy and healthcare policy.

[Access this year's Report here.](#)





MPE - Myeloma Patients Europe

A key milestone this year was the launch of the **Myeloma and AL Amyloidosis Clinical Trial Navigator**, a patient-friendly tool designed to simplify finding clinical trials and understanding the drug development process. The Navigator includes trials for myeloma, MGUS, smouldering multiple myeloma, and AL amyloidosis across Europe, displaying criteria, recruitment status, and locations. It currently hosts 285 trials, with 181 recruiting and 896 clinical trial sites listed.



Since its launch in April 2024, the Navigator has seen nearly 19,000 website visits. In August, Future Rare Disease magazine highlighted the tool in an interview with Dr Solène Clavreul, celebrating its potential to empower patients and carers.

On European Myeloma Day, 27 September 2024, **Myeloma Patients Europe (MPE) expanded accessibility by launching the Navigator in Finnish**, with plans for additional translations in the coming year to break down language barriers for European patients.

This innovative tool marks a significant step forward in enhancing patient access to clinical trials and advancing understanding of clinical research. Find further **[activities of MPE here](#)**.



MPNE - Melanoma Patient Network Europe

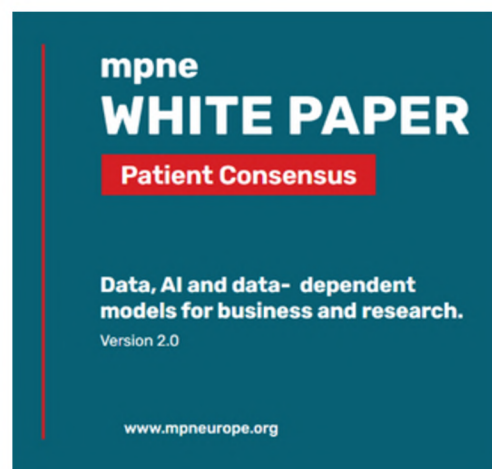
In 2024, **Melanoma Patient Network Europe (MPNE)** made significant strides in patient advocacy, particularly through its **Patient Consensus on Data, AI, and data-dependent business models, developed within the European iToBoS project**. This initiative, which aligns with WECAN’s objectives, focuses on safeguarding patient interests in the evolving landscape of healthcare data. The consensus features 10 core statements addressing critical challenges in data governance, AI, and business models. It emphasises that altruism alone is an insufficient driver for the European Health Data Space (EHDS).

Instead, it advocates for addressing individuals’ tangible needs by ensuring clear value to contributors and robust protection against data misuse. Key recommendations include establishing mechanisms for data vigilance, akin to pharmaco-vigilance, and implementing effective interventions to mitigate harm.



Moreover, the consensus underscores the importance of creating "no-trust environments" where trust is embedded by design, not reliant on people or institutions. These secure frameworks are essential to fostering confidence in data sharing and usage.

The document also outlines areas for future work, including improving data governance models and exploring sustainable business frameworks that prioritise patient benefit. MPNE will continue building on these foundations to advocate for systems that respect and protect patient rights in the age of AI-driven healthcare. Learn more about the **[Patient Consensus here](#)**.



PCE - Pancreatic Cancer Europe



In 2024, **Pancreatic Cancer Europe (PCE)** launched impactful initiatives to improve awareness, access, and support for pancreatic cancer patients. Key events included the **“Getting Our Act Together” Multistakeholder Brainstorming Meeting** (25 June) in Spain, where healthcare professionals, patient organisations, and policymakers identified actionable solutions to improve access to treatment. The **PancreOS Project** roundtable (27 June) highlighted gaps in patient management across Europe, using insights from the European registry network to advance personalised treatments.



PCE also prioritised emotional and nutritional support. During **World Pancreatic Cancer Awareness Month**, PCE hosted a webinar (28 November) offering coping strategies for patients, families, and healthcare professionals. Additionally, its **Nutrition and Pancreatic Cancer** campaign transformed booklets into six multilingual animated videos, extending their reach to diverse European and migrant communities. These resources were shared widely and presented at the **11th ESPEN Symposium** (1–2 December) in Portugal, focused on home nutritional care.

Through these initiatives, PCE continues to address critical care gaps, enhance patient support, and foster collaboration across Europe.

Learn more:

[Getting Our Act Together](#)

[PancreOS Project](#)

[Emotional Support Webinar](#)

[Nutrition Campaign](#)



WCA - World Cup Alliance

In 2024, the **World Cup Awareness (WCA)** organisation achieved major milestones in advancing awareness and improving care for Cancer of Unknown Primary (CUP). WCA **expanded its clinical advisory network** with new members from Japan, Belgium, Wales, France, Switzerland, and China, enhancing its global reach and expertise.



At **ESMO 2024** in Barcelona, WCA successfully **advocated for greater inclusion of CUP in the programme**, resulting in an educational session and a roundtable discussion on precision oncology access. Attended by over 40 clinicians, the event highlighted the importance of CUP-specific strategies. Excitingly, ESMO 2025 will feature a dedicated tumour-agnostic track, and WCA aims to include CUP representation. On 16 October 2025, WCA will also host its first international CUP hybrid conference in Berlin.



WCA co-founder **Warnyta Minnaard (Missie Tumor Onbekend)** has been appointed as project lead for the Netherlands Cancer Mission Hub, advancing cancer control strategies for rare cancers and diagnostics. Meanwhile, co-founder **Tanya Knott (Sarah Jennifer Knott Foundation)** was recognised with the E-NNOVA Health Award 2024 for the SPACE CUP project. This pioneering research, led by **Dr Manel Esteller**, uses AI and transcriptomic analysis to predict the origin of CUP metastases, potentially improving diagnostics, treatment outcomes, and survival rates.

WCA's efforts, including ongoing campaigns to raise CUP awareness globally, exemplify its commitment to transforming patient care through collaboration, innovation, and education.

Learn more: [World Cup Awareness](#).

2024 Funders

We greatly appreciate your support for WECAN's 2024 programmes and initiatives: EuroAct Phase 2 and 3, WECAN Academy, Cancer Survey and the Evidence-Based Advocacy Workshop.



* Funding for these programmes was administered by the European Patient Advocacy Institute

Thank You!

References

WECAN MEMBER ORGANISATIONS

Acute Leukemia Advocates Network
<http://www.acuteleuk.org/>

Childhood Cancer International Europe
<https://ccieurope.eu/>

CLL Advocates Network
<http://www.clladvocates.net/>

CML Advocates Network
<https://www.cmladvocates.net/>

Digestive Cancers Europe
<https://digestivecancers.eu/>

EuropaDonna
<https://www.europadonna.org/>

EuropaUomo
<https://www.europa-uomo.org/>

EURORDIS - Rare Diseases Europe
<https://www.eurordis.org/>

Hereditary Cancer Advocates Europe

International Brain Tumour Alliance
<https://theibta.org/>

International Kidney Cancer Coalition
<http://ikcc.org/>

International Neuroendocrine Cancer Alliance
<http://incalliance.org/>

Lung Cancer Europe
<https://www.lungcancereurope.eu/>

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<http://www.lymphomacoalition.org/>

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<http://www.pancreaticcancereurope.eu/>

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<http://www.sarcoma-patients.eu/en/>

Thyroid Cancer Alliance
<https://www.linkedin.com/company/thyroid-cancer-alliance/>

World Bladder Cancer Patient Coalition
<http://worldbladdercancer.org/>

World Cancer of Unknown Primary Alliance
<https://www.worldcupawareness.org/>

Youth Cancer Europe
<http://www.youthcancereurope.org/>
EDUCATION

WECAN Academy Online Learning Platform.
Available from: <https://academy.wecanadvocate.eu>

WECAN

2024 ACTIVITY REPORT: A YEAR IN REVIEW

Network of 24 umbrella cancer
patient advocacy organisations
active in Europe



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