Activity Report

2025: A YEAR IN REVIEW

WECAN Foundation

Prepared by: European Patient Advocacy Institute gUG

Published on: 24.3.2026

Table of Contents

Introduction & Governance

Programmes & Initiatives

Education

Research

Events

Members News & Activities

Annual Accounts 2025

Acknowledgements

A Letter from the Chair

Over the past year, WECAN has reached a moment that many of us could only imagine when this network first began. Celebrating ten years together whilst formally establishing the WECAN Foundation has been both a moment to celebrate progress and a chance to reflect on how far a community of committed patient advocates can go when it works with trust, purpose and solidarity across Europe.

The establishment of the WECAN Foundation in Spring 2025 was a pivotal step to ensure that WECAN remains sustainable, transparent and able to support its members and partners for many years to come. This transition was made possible thanks to the dedication and hard work of many across our network, and I would like to express my sincere gratitude to everyone who contributed their time, expertise, and belief in our shared vision.

Our 10th Anniversary celebration in Berlin in October was a particularly meaningful milestone we got to celebrate with so many of you. Looking back over a decade, it was inspiring to see how WECAN has grown from a small group of advocates into a recognized European voice for cancer patient advocacy. More importantly, it was a vivid reminder that this progress has always been driven by our members and by the patients and communities they represent.

One of the most encouraging achievements of 2025 was the recognition of the EuroACT project, awarded Best Poster Presentation at ESMO Congress. By analysing inequities in access to research across countries and cancer types, EuroACT showed how patient-led, data-driven advocacy can contribute to more inclusive and equitable research policies at the European level. It stands as a clear example of how evidence and advocacy - when combined - can shape important conversations in cancer research and policy.

The WECAN Academy in Rome last June, brought together over 80 patient advocates and 16 speakers from across Europe. Beyond the numbers, the Academy continues to be a space where advocates gain confidence, skills and connections that strengthen their ability to speak for patients in national and European forums. Seeing this next generation of advocates learn from one another and build lasting collaborations and friendships is one of the most rewarding aspects of WECAN’s work.

As we look to the years ahead, WECAN will continue to build capacity among advocates, foster collaboration across borders and ensure that the patient voice remains central to European cancer policy and research. Together, we can continue shaping a more equitable, inclusive, and sustainable future for all those affected by cancer.

To our member organisations, patient advocates, sponsors, and policy partners – your trust, commitment, and collaboration remain the foundation of WECAN’s success. Thank you for walking this journey with us.

With heartfelt appreciation and optimism for what lies ahead, I wish you all a joyful and peaceful 2026.

Alex Filicevas

Chair, WECAN Board of Directors

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 between pan-European cancer patient umbrella organisations, on the principle of subsidiarity.

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.

WECAN Overview

The Workgroup of European Cancer Patient Advocacy Networks (WECAN) brings together 23 committed umbrella cancer patient advocacy organisations from across Europe.

WECAN represents patients across all cancer types, uniting efforts at a pan-cancer level to drive meaningful improvements and advocate for policies and practices that benefit every patient.

The WECAN network celebrated its 10th anniversary and formally established as a Foundation in 2025, marking a significant milestone in our ongoing mission to strengthen our reach and impact across Europe.

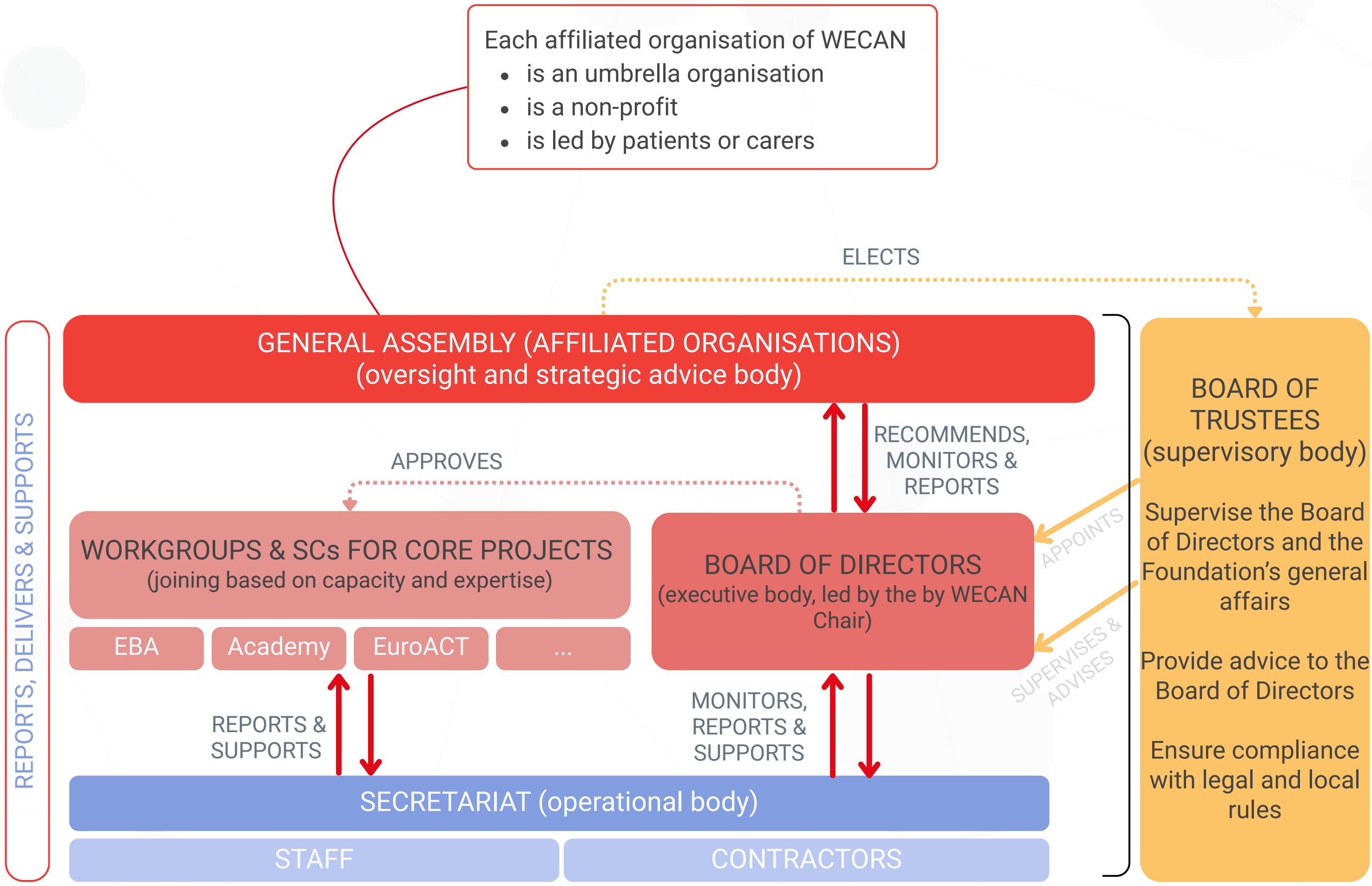
Our Network

WECAN is composed of leaders from pan-European cancer patient umbrella networks. In 2025, its network included 23 organisations representing over 27 different cancer types.

- 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
- World Bladder Cancer Patient Coalition
- Youth Cancer Europe
- World Cancer of Unknown Primary Alliance
- Hereditary Cancer Advocates Europe

WECAN Foundation
Governance

WECAN decided to establish itself as a Foundation in 2025 in the Netherlands to formalise operations, enhance credibility and ensure accountability. This structure fosters stakeholder trust and safeguards long term initiatives while enabling transparency and compliance with cross-border legal and financial requirements.



Each affiliated organisation of WECAN
- is an umbrella organisation
- is a non-profit
- is led by patients or carers

ELECTS

GENERAL ASSEMBLY (AFFILIATED ORGANISATIONS)
(oversight and strategic advice body)

RECOMMENDS, MONITORS & REPORTS

APPROVES

WORKGROUPS & SCs FOR CORE PROJECTS
(joining based on capacity and expertise)

EBA | Academy | EuroACT | ...

BOARD OF DIRECTORS
(executive body, led by the by WECAN Chair)

APPOINTS

SUPERVISES & ADVISES

BOARD OF TRUSTEES
(supervisory body)

Supervise the Board of Directors and the Foundation's general affairs

Provide advice to the Board of Directors

Ensure compliance with legal and local rules

REPORTS & SUPPORTS

MONITORS, REPORTS & SUPPORTS

SECRETARIAT (operational body)

STAFF | CONTRACTORS

REPORTS, DELIVERS & SUPPORTS

The General Assembly represents all affiliated organisations, defining strategic priorities and electing the Foundation's leadership. The Board of Trustees serves as the supervisory body, providing oversight and ensuring that all activities comply with legal, ethical, and strategic standards. The Board of Directors manages day-to-day operations, implements strategy, and oversees resource management. The Secretariat facilitates coordination and administration, while dedicated Workgroups drive progress on specific projects and initiatives.

WECAN
Foundation

Over the Years

Established in 2015, WECAN has united Europe's cancer patient community to create lasting impact.

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**

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.

2025

The **WECAN Foundation** was established as an independent, not-for-profit entity, marking a significant step toward ensuring strong governance, sustainability, and long-term impact for cancer patient advocacy across Europe. **WECAN celebrated the 10th anniversary** in Berlin, bringing together more than 90 participants to honour a decade of collaboration, growth, and achievements within the community. WECAN is leading evidence based projects, its outstanding research has granted EuroACT the best poster award at ESMO25.

WECAN Foundation Board

The WECAN Board of Directors, elected in January 2025, brings strong expertise and commitment to guide the Foundation through its first phase. The Board of Trustees, elected by WECAN affiliates, oversees the Directors and Secretariat to ensure the Foundation's operates legally and mission-driven.

Board of Directors

Alex Filicevas
Chair
World Bladder Cancer Patient Coalition

Gilly Spurrier
Melanoma Patients Network Europe

Anita Kienesberger
Childhood Cancer International Europe

Karin Kastrati
International Kidney Cancer Coalition

Ariane Weinman
EURORDIS - Rare Diseases Europe

Mark McDonnell
International Neuroendocrine Cancer Alliance

Erik Briers
EuropaUomo

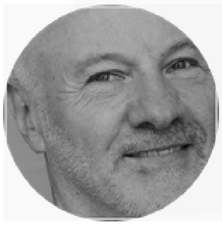
Board of Trustees

Kathy Redmond
Chair

Jean-Yves Blay

Elizabeth Macintyre

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

Alex Filicevas

2025
World Bladder Cancer Patient Coalition

2025
PROGRAMMES AND INITIATIVES

The year 2025 has been a defining and transformative period for WECAN. In addition to our ongoing engagement in a wide range of projects, initiatives, partnerships, and high-level European patient advocacy discussions, we also reached several major milestones.

WECAN Academy

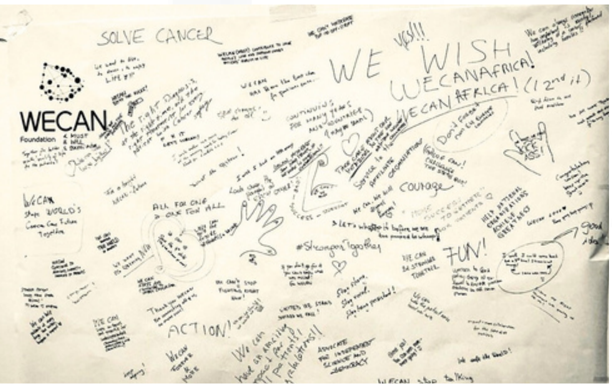
WECAN delivered a vibrant and well-received Academy in Rome. This year's programme offered practical training, shared learning, and capacity-building opportunities designed to empower patient advocates and strengthen the work of organisations across the network.

WECAN Members meeting at ESMO 2025

During ESMO 2025, WECAN held a stakeholder meeting to update partners on our progress. We shared key developments, and outlined upcoming projects and priorities.

EuroACT : ESMO 2025 best poster award

EuroACT was honoured with the Best Poster Award at ESMO 2025. This recognition reflects the quality, relevance, and credibility of our work, as well as the importance of patient-led initiatives.



WECAN 10th anniversary

WECAN's 10th anniversary in Berlin, bringing together more than 100 cancer patient advocacy leaders from across Europe. This milestone gathering highlighted a decade of collaboration, shared achievements, and progress driven by the commitment of our community.

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**

WECAN Academy: Empowering advocates to lead change through knowledge, connection & collaboration

WECAN Academy

The WECAN Academy 2025 brought together more than **70 passionate cancer patient advocates** from across Europe and beyond for a transformative in-person experience in Rome.

Participants engaged in one of two tailored tracks:

- **WECAN SmartStart** – for emerging patient advocates
- **WECAN MasterClass** – for experienced leaders in patient advocacy

Across 4 days, **23 training sessions** were held with **18 expert speakers** who shared insights not only as trainers but many of them also as peers, enriching the collaborative spirit of the event.

SmartStart participants started the academy with foundational topics which laid the groundwork for more in-depth discussions in the following days. These included:

- **Health Economics**
- **Drug Development & Inequities**
- **Healthcare Ecosystems and Stakeholder Management**
- **Ethics in Advocacy**

WECAN Academy

Days 2 & 3 focused on **Evidence-Based Advocacy and Sustainability**, and **Research, Governance, and Policy**, exploring practical topics for for their advocacy work such as NGO Governance, HTA 4 Patients and Conversation with Industry on Pharmaceutical Policy.

This content deepened participants' understanding of the systemic and regulatory landscape shaping cancer advocacy.

On the final day, **MasterClass participants** engaged in advanced discussions on:

- **Patient-Reported Outcomes (PROs)**
- **Advanced Evidence-Based Advocacy**
- **Health Inequities and Systemic Barriers**

The day fostered high-level dialogue and peer learning among seasoned advocates.

> ***I learned so much about advocacy and met wonderful people. Thank you for this fantastic experience!***

The feedback received from participants reflects a high level of satisfaction and engagement from participants. With the sessions being rated as:

11	7	4
rated **4.5 - 4.9 / 5**	rated **4.0+ / 5**	rated **3.6 - 3.9 / 5**

The WECAN Academy delivered more than just **high-quality training**, it fostered **invaluable connections**, empowered advocates, and strengthened a vibrant, cross-border community of changemakers. Its success reinforces WECAN's role as a **leading force in cancer patient advocacy**.

> ***The quality of the Academy keeps improving every year. I'm thankful for the chance to share my story and learn from others.***

WECAN is committed to **expanding access to high quality advocacy training** for both emerging and experienced patient advocate leaders.

The WECAN Academy is not just a one-time event; it's a **flagship initiative that fuels long-term capacity building across Europe and beyond**. With continued sponsorship, we can scale momentum, empowering more advocates, amplify more voices, and drive systemic change in healthcare.

Available Courses on

Academy.wecanadvocate.eu

WECAN´s Evidence-Based Advocacy Programme

WHY PATIENT EXPERIENCE DATA (PED) MATTERS NOW

The new **European Medicine Agency Reflection Paper on PED reinforces a clear message:** **lived experience must become a systematic, high-quality evidence source throughout the entire lifecycle of medicines.** It emphasises that PED—data directly reflecting how patients feel, function and what they value—plays an essential role in shaping meaningful trial endpoints, strengthening regulatory decisions, informing reimbursement, and improving real-world care .

Yet, the **paper also highlights major gaps:** PED is still not collected consistently, methodologies vary, and many patient organisations lack the resources, skills or frameworks to generate robust evidence.

This Patient Experience Data Course

directly responds to these gaps. It equips patient organisations with the practical tools to generate high-quality lived-experience data, from PROs and PROMs to qualitative insights and preference studies. By building this capability, patient organisations move from being consultees to becoming evidence-driven partners—bringing structured patient experience into research, regulation, and access decisions where it is urgently needed.

THE COURSE AIMS TO:

- → Empower patient organisations to generate high-quality PED.
- → Strengthen advocacy with robust, patient-driven evidence—not just stories.
- → Build practical skills in data types, study methods, and qualitative/quantitative tools.
- → Provide clear guidance on data governance, ethics, and responsible evidence use.
- → Equip advocates to influence research, policy, and access decisions with confidence.
- → Enable meaningful collaboration with industry, regulators, and researchers.
- → Boost the use of real-world insights to improve medicines development and patient care.

Education

WECAN´s Evidence-Based Advocacy Programme

MODULE 1 **gives learners a solid foundation in:**

- What PED is and how it expands traditional evidence.
- The different forms of PED, from PROs to preference studies.
- How PED is collected using qualitative and quantitative methods.
- Real examples of PED influencing decisions in research and regulation.
- Stakeholder insights on why PED matters for clinicians, researchers, industry, regulators, and HTA bodies.

MODULE 2 **teaches learners to:**

- Understand PROs: what they measure, why they matter, and how they differ from PROMs & PREMs.
- Use PRO measures effectively: select, design, and tailor tools using item libraries.
- Develop high-quality PRO instruments: patient involvement, validation steps, and practical considerations.
- Learn from real case studies: PROs in acute leukemia and hereditary cancer

MODULE 3 **teaches learners to:**

- Understand Patient Preference Data and why it complements clinical and PRO data.
- Use qualitative & quantitative methods to capture what matters most to patients.
- Design and implement PPD studies, including DCEs.
- Learn from real practice through a leukemia case study showing how PPD informs decisions.

Module 1,2 & 3 were launched in 2024

- *Each module includes presentations, real-world case studies, key takeaways, and interactive quizzes to enhance learning.*
- *The course supports capacity building within the patient community, enabling improved evidence generation and advocacy for all cancer patients.*

FINAL MODULE 4 “PED IN PRACTICE”

What is Module 4

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.

Current Status:

The final part of the course is in the last phase of content development and recording, with the course being launched in February 2026.

WHAT'S NEXT?

Sustainable Data model course (across diseases)

- Acquaint POs with different models of with different models of community-led data stewardship
- Teach POs how to design a forward-thinking data strategy aligned with their mission and capacity
- Recognise how small-scale steps can evolve into platforms that support evidence, advocacy, and sustainability
- Delivered through interactive modules and case studies co-developed with patient organisations across disease areas

Research

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

CANCERSurvey: PED along the cancer patient pathway advocacy

Evidence-Based Advocacy

There is currently a lack of consistent and standardised measures, which limits the ability to compare patient experiences across different cancer types. As a result, it becomes challenging to identify best practices in care, ensure equitable treatment across cancer types, and inform healthcare policies and treatment approaches that truly address patients' needs.

Without ensuring an optimal patient experience, improvements in health and well-being are limited.

Patient Experience Data (PED) has gained increasing importance in drug development, regulatory decisions, and health technology assessments.

PED can guide crucial decisions in research and clinical practices, bearing in mind the continuum of care.

Lack of consistent and standardised data collection, making comparison of patient experiences across cancer types ineffective.

To identify best practices of care and equitable care provision across cancer types, the **CANCERSurvey** gathers and compares PED along the patient pathway.

The CANCERSurvey seeks to generate both community-wide and disease-specific insights for advocacy purposes. Its objectives also include fostering collaboration on the project and actively involving representatives from WECAN member organisations in the survey development process.

The CANCERSurvey is structured in 4 Phases:

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**

Phase 1 →	**Phase 2** →	**Phase 3** →	**Phase 4**
Research, survey design and development	Survey distribution and data collection	Data analysis	Scientific dissemination, Advocacy Support & Sustainability

Updates & Next Steps

Since September 2025, WECAN has gathered enough funding for Phases 1 & 2 of the project, and the project has been reignited at ESMO 2025. The Steering Committee has been reinstalled and a first conceptual draft of the survey will be ready in the first quarter of 2026. Together with the Steering Committee, we will build on the topics that were identified during the workshop that took place in 2024 with 40 patient advocates, carers, and clinicians from 20 European countries.

EuroACT: Turning data into evidence for advocacy

The European Atlas on Clinical Trials in Cancer and Hematology (EuroACT) project maps disparities in Clinical Trials, assess how Patient-Reported Outcomes (PROs) and Health-Related Quality of Life (HRQoL) measures are collected and reported, and identify gaps in existing research.

In 2025, the EuroACT project continued its evolution by completing and enhancing Phases 3 and 5. The first part of the year focused on improving the clinical trial database, integrating ongoing trial data, and progressing toward the project's publication and stakeholder dissemination goals.

You may find more details in the WECAN website, scan the QR code.

European Atlas on Clinical Trials in Cancer and Haematology (EuroACT): Mapping Research and Equity Across Europe

2309P

L. Puga[1*], M. Cases Escute[2], A. Imre[3], R. Giles[4], M. Piggin[5], S. Leto di Priolo[6], M. Racovita[7], L. Ruth Wogu[8], J. Geissler[1], D. Hosszú[3], Á. Józwiak[3], T. Ágh[3], J. G. Pitter[3], A. Plate[2]

[1]European Patient Advocacy Institute, Germany, [2]European Patient Advocacy Institute, Germany, [3]Syreon Research Institute, Hungary, [4]VHL Europa, Netherlands, [5]PNH Global Alliance, Netherlands, [6]TUTOR – Associazione Tumori Toracici Rari, APS ETS, Italy, [7]Myeloma Patients Europe AISBL, Belgium, [8]European Sickle Cell Federation, Ireland

* lis.puga@patientadvocacy.eu

EuroACT

WECAN

syreon Research Institute

ESMO 2025 Best Poster Award

This recognition was granted to our poster on trial-access inequities and the role of PRO implementation, selected from 2,543 posters presented at ESMO, one of the world's largest oncology congresses. The award recognises the poster's clarity of presentation, methodological rigour and strong relevance to current oncology practice and policymaking.

EuroACT
European Atlas on Clinical Trials in Cancer & Hematology

Collaboration with OECD

The Organisation for Economic Co-operation and Development (**OECD**) contacted us after reviewing the EuroACT work. The robustness and methodological rigor of the EuroACT dataset were recognised as valuable for informing OECD's Delivering Hight Value Cancer Care report.
EuroACT insights were used in two critical chapters :

- Chapter 3 explores cross-country disparities in cancer clinical trials across the EU.
- Chapter 5 uses EuroACT evidence to assess the use of patient-reported outcomes (PROs) in oncology trials, highlighting gaps in how patient perspectives are captured and reported.

This contribution highlights the relevance of patient-driven, systematically analysed clinical-trial data for identifying inequalities and supporting evidence-based policy development across Europe.

Peer-reviewed publication on EuroACT methodology

The first EuroACT peer-reviewed manuscript was published in **Frontiers in Pharmacology.** This paper presents the novel methodology developed to enable systematic extraction, harmonisation and analysis of clinical trial data across European registries. The publication of the methodology validates the rigour of the EuroACT approach and provides the foundation for all subsequent analyses.

Preprints on solid tumours and haematology

Two additional EuroACT manuscripts are now publicly available as preprints with **The Lancet.** The solid tumours preprint analyses 20,658 clinical trials across 12 tumour types, and the haematology and rare diseases preprint analyses 6,809 trials covering a wide range of conditions, including acute leukaemia, CLL, CML, MPNs, lymphomas, multiple myeloma, haemophilia, thalassaemia, sickle cell disease and others.

EuroACT
European Atlas on Clinical Trials in Cancer & Hematology

3 Oral Presentations

1 **6th EORTC Quality of Life in Cancer Clinical Trials Conference** (May)

2 **CML Horizons Hybrid Meeting 2025** (May)

3 **EHA CRTH Workshop** (September)

The oral presentations focused on explaining the methodological approach and recent advancements in data collection and analysis.

4 Interviews and Multi-stakeholder meeting to interpret and disseminate EuroACT data

After the EuroACT Steering Committee met in April 2025 to interpret these results in a “Challenge Meeting”, four focused group interview workshops with patient advocates, HTA members, PRO experts, industry representatives, and regulators were conducted, complemented by a multistakeholder workshop in October 2025. Together, these meetings enabled a full exchange of perspectives and were essential for validating and contextualising the project findings across all stakeholder groups.

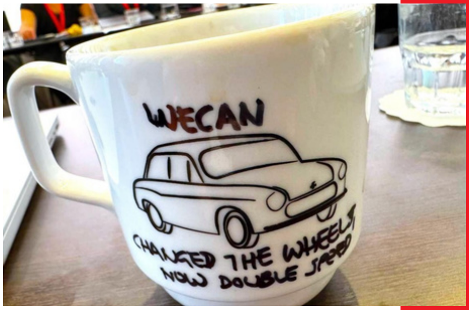
Thank you

We thank the EuroACT Steering Committee and the wider European community engaged in improving equity and patient-centred outcomes. We also thank the organisations that contribute with the interpretation of the results: AIPIT aps (Associazione Italiana Porpora Immune Trombocitopenica aps); ALAN (Acute Leukemia Advocates Network); EMA – European Medicines Agency; EORTC; Europa Donna; Hungarian HTA; ICHOM; IQWiG – Drug Assessment Department; Irish Haemochromatosis Association; KBS; Kidney Cancer Sweden; Kulich Consulting Bt; Lymphoma Coalition; MPE (Myeloma Patients Europe); Norwegian Medicines Agency; OECD; Sickle Cell and Thalassaemia Ireland; Stiftung Lichterzellen; T.U.T.O.R (Rare Thoracic Tumours); Thalassaemia International Federation; University of Hertfordshire; VHL Europa (Von Hippel–Lindau Alliance Europe).The views expressed are those of the individual contributors and do not necessarily reflect those of their respective organisations.

Members Meeting

WECAN Members gathered together in Warsaw on May 18 and 19, celebrating and announcing that WECAN had officially become a legal entity. The meeting happened in connection with the ECHoS Cancer Mission Hub Event.

The ECHoS project (Establishing of Cancer Mission Hubs: Networks and Synergies) is a European Union initiative funded under the Horizon Europe programme that aims to strengthen collaboration in cancer research, care, and policy across Europe by creating a network of National Cancer Mission Hubs (NCMHs) in Member States and Associated Countries.



10-Year Anniversary

On 18 October 2025, WECAN celebrated a decade of collaboration, growth, and impact within the European cancer patient advocacy community in Berlin.

More than 90 participants attended the event, which offered an opportunity to reflect on WECAN's achievements over the past ten years and to look ahead to the future of the WECAN Foundation and its shared mission.

The evening opened with a warm welcome from Alex Filicevas, Chair of WECAN, who revisited key milestones from the organisation's 10-year journey. The programme also featured video messages from Silke Launert, Parliamentary State Secretary at the German Federal Ministry of Research, Technology and Space, and Kathy Redmond, WECAN Trustee.

An engaging panel discussion followed, entitled "WECAN Shape Europe's Cancer Care Future Together," moderated by Jan Geissler and featuring Gilliosa Spurrier-Bernard, Hugo R. Soares, Madeline Pe, Marzia Zambon, and Wafae Iraqi. The discussion explored how collaboration between advocates, researchers, and policymakers continues to shape a more equitable and patient-centred approach to cancer care in Europe.

Members News & Activities

WECAN is delighted to highlight the remarkable achievements of the cancer patient advocacy community in 2025. Throughout the year, our member organisations have made meaningful progress in strengthening patient advocacy and driving initiatives that have improved the lives of people with cancer across Europe

CDDF Multi-stakeholder Workshop on New Modalities in cancer drug development: 31 Mar – 1 Apr 2025 in Brussels

From 20–22 May 2025, several WECAN members attended the Polish Cancer Mission Fair and the associated ECHoS synergies event in Warsaw. WECAN led a workshop focused on impact modelling in Quality of Life and contributed to multiple sessions throughout the event, showcasing the value of patient input in cancer-related initiatives.

From 23–24 June 2025, members of the Board represented WECAN at the ECHoS 2 Writing Group Meeting in Brussels. This gathering explored potential areas where WECAN members might contribute to the EU-funded ECHoS 2 project. The initiative aims to strengthen collaboration across local, national, and European levels by supporting National Cancer Mission Hubs (NCMHs).

Representatives of the WECAN Board attended the EHA Congress (12–15 June 2025), ESMO Congress (17-21 October 2025), and the first annual meeting of EUnetCCC (6-7 November).

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 2025, ALAN made significant strides in **advocacy**, **education**, **awareness**, and **research** for acute leukemia patients and carers.

The network expanded to **61 members across 55 countries**, with the addition of 2 new members from China (Hongmian Cancers & Rare Disorders Charity Foundation of Guangzhou) and Ghana (Empowerment for Sustainable Livelihood (ESL)), and strengthened its digital presence, with notable growth on social media.

As in previous years, **key awareness initiatives** included the **#BeLeukemiaAware** campaign, **World Leukemia Day** and **Blood Cancer Awareness Month**, promoting public awareness, early detection and patient empowerment.

In 2025, ALAN also ran a specific campaign for International Men Health Week (9-16th June) to encourage involvement and awareness among men. The campaign demonstrated high engagement, with a reach increase of over **+3,000%** and a rebalancing of the gender target, with the **male-identifying gender share rising from 33% to 52.5% (+59%).** This confirms the relevance of the initiative and suggests that it should be maintained and strengthened in 2026.

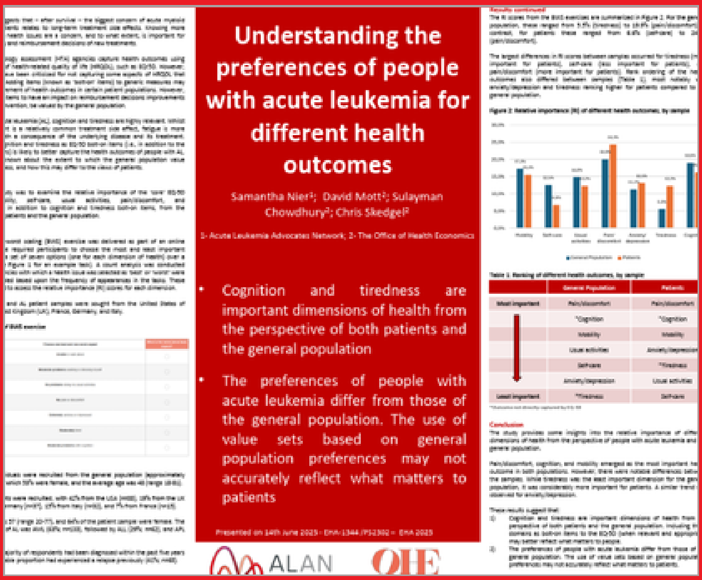

Treatment outcomes preferences: What matters to patients with acute leukemia?

Jan Geissler[1], Samantha Nier[1], Marieke Heisen[2], Niroshah Suthakharan[2]
[1] Acute Leukemia Advocates Network (ALAN)
[2] Patvocates

Scientific Working Group: Quality of life and symptoms,
EHA congress,, Thursday, 12 June 2025, p270-3, 15:15, Coral 3

ALAN gave a number of presentations at the **EHA 2025 Congress** in Milan between 12th to 15th June 2025, showcasing data from their evidence-based advocacy work. These included patient preference studies, generating crucial insights on quality of life and treatment impacts.

This included the oral presentation **"Treatment outcomes preferences: What matters to patients with acute leukemia?"**, and the poster presentation **"Understanding of the Perspectives and Preferences of Informal Carers of People with Acute Leukemia: Insights from a Qualitative Study."**, among many others.


Understanding the preferences of people with acute leukemia for different health outcomes

Samantha Nier[1]; David Mott[2]; Sulayman Chowdhury[2]; Chris Skedgel[2]

1- Acute Leukemia Advocates Network; 2- The Office of Health Economics

- Cognition and tiredness are important dimensions of health from the perspective of both patients and the general population
- The preferences of people with acute leukemia differ from those of the general population. The use of value sets based on general population preferences may not accurately reflect what matters to patients

Presented on 14th June 2025 - EHA-1344 /PS1302 - EHA 2025

CCI Europe - Childhood Cancer International Europe

2025 was a transformative year for **CCI Europe**. Guided by our vision of ***a world where everyone affected by childhood cancer is supported and able to thrive, free from lasting impact,*** we focused on policy advocacy, standard-setting, survivor empowerment, and collaboration with clinical, research, and patient advocate partners. We actively brought lived experience into European frameworks, connecting families, survivors, clinicians, and policymakers to drive systemic change for children and adolescents with cancer.

Key Initiatives & Achievements in 2025

European Standards of Care for Children and Adolescents with Cancer

CCI Europe, together with SIOP Europe, celebrated the release of the revised **European Standards of Care**, a four-year effort involving 45 patient advocates and healthcare professionals from 22 countries. Covering amongst others treatment, psychosocial care, survivorship, cross-border care, and education, the Standards provide evidence-based guidelines for state of the art, high quality care across Europe. CCI Europe ensured the perspectives of young people and families are central to every chapter.

European Standards of Care

For Children and Adolescents with Cancer

2025

Position Paper for the Multiannual Financial Framework (MFF) 2028 - 2034

In August 2025, CCI Europe and SIOP Europe published a joint **position paper on the MFF 2028 - 2034**. It calls on EU institutions to prioritise childhood cancer and outlines **four key recommendations**: boosting drug development and innovation, implementing care networks, enabling data-sharing and AI tools, and securing sustainable grants for patient organisations. Our advocacy highlights the need for long-term funding to turn policy commitments into real improvements for children and families.

CCI Europe - Childhood Cancer International Europe

End of the EU-CAYAS-NET Project and Survivorship Outcomes

From 2022 - 2025 CCI Europe coordinated one of the European Commission's flagship projects, the European Network of Youth Cancer Survivors (EU-CAYAS-NET). The **completion of EU-CAYAS-NET** marked a major milestone in survivorship advocacy. CCI Europe contributed to building the **EU-CAYAS-NET Ambassador programme**, consisting of 55 survivor advocates from 29 countries and to developing resources on quality of life, mental health, education & career support as well as transition and long-term follow-up care. These **resources** now serve as tools for survivors, families, healthcare professionals, and advocates across Europe.

CCI Europe Conference 2025 in Budapest

In May 2025, CCI Europe hosted the **15th CCI Europe Conference in Budapest**, bringing together 131 participants, including patient advocates, parents, and survivors. Sessions focused on peer support, research engagement, and network-building. The conference provided a platform for sharing best practices, strengthening collaborations, and shaping the strategic agenda for the coming years.

CML Advocates Network

In 2025, CMLAN welcomed **five new member organisations**, strengthening the network's geographic balance, collaborative reach and cultural diversity. These include: *LMCRo* – Romania; *Team CML Japan* – Japan; *NuanBai Leukemia China* – China; *Leukemia Research Foundation (LRF)* – USA; and *AMACAS-LMC* – Cameroon.

CML Horizons 2025 took place from 23–25 May in Bucharest, gathering **more than 140 participants from 55 countries**. The meeting offered a balanced mix of:

- **Scientific updates**, which helped patient advocates refresh their medical knowledge and understand the evidence behind current clinical decision-making,
- **Practical advocacy training**, with discussions grounded in practical examples shared by participants, highlighting different approaches across countries, and
- **Space for community connection**, enabling regional groups to discuss access issues, barriers to monitoring, reimbursement challenges, and the varying levels of awareness among clinicians and the public.

In 2025, we took a major step forward by **transitioning the CML Online Academy into the new Blood Cancer Patient Advocates Academy** a shared education platform developed together with ALAN, CLLAN and MPN-AN.

From January to mid-November 2025, the participation and reach:

- **115 new users** created accounts
- 82 of these enrolled in at least one course
- Across all users, **131 total course enrolments** were recorded
- Participants came from **42 countries**

The **Patient Preference Study** completed data collection in 2025, and two abstracts of the initial findings were at **SOHO 2025** (USA/Canada data) & **ESH 2025** (UK/Spain data).

World CML Day 2025 brought together organisations from across all regions. The theme, "*Equity in Action*", encouraged groups to highlight the differences in diagnosis, monitoring, and treatment access, and to share messages about fairness and early care.
CMLAN provided a **toolkit and posting calendar** which was adapted by several groups into their local languages, making it easier for them to reach their communities.

DIGESTIVE CANCERS
EUROPE

DiCE- Digestive Cancers Europe

Digestive Cancers Europe (DiCE), a proud WECAN member and the only pan-European organisation supporting people affected by digestive cancers, marked **2025 as The Year of the Patient**, working with the patient community to strengthen their voice, address unmet needs, and promote change in advocacy, research, awareness, and care across Europe.

ENTERO Policy Initiative

After ENTERO 2024, DiCE brought the rise of early-onset digestive cancers to the European Parliament, where MEPs Jerkovic and Andriukaitis joined experts and people with lived experience to urge better awareness, quicker diagnosis, and age-appropriate care, resulting in clear recommendations for policymakers and health systems.

Patient-Led Research and Publications

These resources support DiCE's wider work on early-onset digestive cancers, informing the public, healthcare teams, and decision-makers.

Early-Onset Colorectal Cancer Study

DiCE co-authored a qualitative study published in BMC Gastroenterology, capturing the experiences of 47 people diagnosed with colorectal cancer under 50 across seven European countries. It highlights the clinical, emotional, and practical challenges faced by younger patients.

You're Young, But It Might Be Cancer

A collection of testimonies from young colorectal cancer survivors, raising awareness of early symptoms and delayed diagnosis.

The Last Thing I Expected At This Age

Stories of resilience and advocacy from young people living with digestive cancers.

To further bring visibility to these experiences, DiCE launched a series of patient-led books co-created with young survivors, caregivers, and advocates:

Finding Your Way: Living Well Beyond Colorectal Cancer

A supportive guide for life after treatment, covering nutrition, fatigue, sexuality, mental health, body image, and returning to work.

Life with Lower Anterior Resection Syndrome (LARS)

This guide supports people living with LARS by explaining symptoms, coping strategies, diet, emotional well-being, and communication with healthcare professionals.

Supporting Your Mind: A Patient Guide Through Digestive Cancer

A patient-centred guide addressing emotional health, communication, stoma care, sexuality, fertility, diet, and life after treatment.

Europa Donna

Europa Donna – The European Breast Cancer Coalition is an **independent nonprofit organisation** whose members are affiliated groups from countries throughout Europe. The Coalition works to **raise awareness of breast cancer** and mobilise the support of European women in pressing **for improved breast cancer education, appropriate screening, optimal treatment, and increased funding for research.** Europa Donna has national groups in **47 member countries**.

Member News & Activities

In 2025, Europa Donna strengthened its educational and advocacy initiatives across Europe:

EmpowerED: The Breast Cancer Advocacy Academy

Our modular digital platform will be officially launched in November, offering comprehensive training on prevention, screening, early detection, genetic testing, AI applications, treatment, clinical trials, survivorship, advocacy management, caregiving, and metastatic breast cancer. Additional modules address emerging topics in breast cancer research and patient-centred advocacy. The platform will be continually updated.

Advocacy Training Course – Milan (March 28–30)

Over 80 advocates from 35 countries attended a 2½-day intensive course. The course featured interactive workshops, expert-led scientific lectures, and peer-to-peer exchanges, fostering stronger advocacy skills and collaboration across national groups.

MBC Advocacy Webinar – May 23

Engaged 51 participants in focused discussions on metastatic breast cancer, sharing knowledge on patient needs, emerging therapies, and advocacy strategies to improve care access.

Educational Roundtables

- **June 5:** Hereditary breast cancer, led by Donjeta Zeqa (ED Albania). Explored complex realities of BRCA1/BRCA2 mutations, cascade testing, and the emotional impact of genetic testing.
- **July 17:** Patient involvement in research, led by Cristina Guerrero Paez (ED Netherlands). Focused on integrating patient perspectives in research and advocacy to influence policy and access to treatments.
- **November 10:** Biomarkers: A Game Changer for Breast Cancer Diagnosis and Treatment, led by Prof. Carlos Caldas. Highlighted advances in precision medicine and the role of biomarkers in guiding more effective and personalised therapies.

Europa Donna

Forum Mapping Project
Conducted extensive surveys and online discussions with country groups to identify shared challenges and opportunities, fostering cross-border collaboration and potentially forming regional subgroups to strengthen coalition-wide advocacy.

High-Level Policy Event – European Parliament, Brussels (October 15)
Europa Donna presented a motion to officially declare 15 October as European Breast Health Day, marking a historic milestone for women's health in Europe. The event was hosted by MEPs Romana Jerkovic and Nikos Papandreou and brought together leading EU figures and health experts, including President of the European Parliament Roberta Metsola and former European Commissioner for Health and Food Safety and past President of Europa Donna Stella Kyriakides. The event emphasised a shared commitment to prevention, equity, and access to breast health across Europe. This day represents a key step in making breast health a European priority, ensuring that every woman has access to early detection, prevention, screening, and the right to health.

Participation in Events
Europa Donna and Executive Director Marzia Zambon actively represented WECAN at key 2025 events:

- **WECAN Retreat – Warsaw**: Participated in strategic discussions and workshops aimed at strengthening European cancer advocacy networks and fostering collaboration between member organisations.
- **EchoS Launch – Warsaw**: Attended the official launch of the new initiative, showcasing WECAN's commitment to innovative cancer advocacy projects and cross-border cooperation.
- **WECAN Members Meeting – Berlin**: Engaged with member groups in peer discussions and knowledge-sharing sessions, focusing on best practices and joint advocacy strategies for improved cancer care.
- **Celebration of 10 Years – Berlin**: Marzia Zambon spoke at this milestone event, reflecting on a decade of WECAN achievements, highlighting ongoing challenges, and emphasising the future vision for European cancer advocacy.

Through these activities, Europa Donna continues to empower advocates, enhance knowledge-sharing, and drive meaningful change in breast cancer care across Europe.

EURORDIS

EURORDIS – Rare Diseases Europe is a non-profit alliance that brings together rare disease patient organisations to work together to improve the lives of **over 30 million people living with a rare disease in Europe** (there are over 6000 types of rare diseases including rare cancers).

Among its main advocacy activities, over the past two decades EURORDIS has been calling for the establishment of European Reference Networks (ERNs) of highly specialised healthcare professionals to pool scarce knowledge and expertise across Europe on a wide range of rare diseases, with a view to reducing the diagnostic odyssey, providing adequate treatment and care to patients wherever they live in Europe, and enhancing knowledge and data sharing.

In March 2017, 24 ERNs were launched, clustered according to broad domains of rare diseases. In the field of rare cancers, there are four ERNs: PaedCan (paediatric cancers), EURACAN (rare adult solid tumours), EuroBloodNet (rare haematological diseases, including rare haematological malignancies), and GENTURIS (genetic tumour risk syndromes). EURORDIS organised the establishment of patient groups for each ERN and has provided continuous support for patient engagement. In January 2023, it officially launched the Rare Cancer Advocates Network (RCAN), bringing together 32 rare cancer patient organisations involved across ERNs relevant to rare cancers to formalise their advocacy work.

Most RCAN members have a national scope, while 11 are European patient federations (including EURORDIS) and members of WECAN, and as such help to foster outreach.

RARE CANCER ADVOCATES NETWORK

CALLING FOR A UNIFIED APPROACH
TO THE INCLUSION OF CHILDHOOD CANCERS
AND RARE ADULT CANCERS
IN NATIONAL CANCER CONTROL PLANS
IN EUROPE

A major milestone was reached in May 2025 with the **publication of the RCAN position paper**, which **calls on national health authorities across Europe to include dedicated and distinct sections on childhood cancers and rare adult cancers in their National Cancer Control Plans (NCCPs)**. Only a few NCCPs currently do so, and this gap contributes to significant inequalities in healthcare.

This position paper is the result of a year and a half of work with volunteer patient advocates. It offers concrete, evidence-based proposals to support policymakers, clinicians, and patient organisations working to make NCCPs more equitable and inclusive.

Access the paper here: https://www.eurordis.org/publications/rare-cancer-advocates-network-position-paper/

EURORDIS

Rare Cancer Advocates Network (RCAN)
A unified approach to the inclusion of childhood cancers and rare adult cancers in National Cancer Control Plans in Europe.

1 in 5 cancers are RARE

Incidence of rare cancers is less than 6 per 100,000 people a year. About 5.1 million people live with a rare cancer in Europe.

OBJECTIVE

The Rare Cancer Advocates Network (RCAN) asks that each National Cancer Control Plan (NCCP) in Europe includes dedicated and distinct sections on childhood cancers and on rare adult cancers respectively to address patients' and survivors' various challenges throughout their journey, and foster research for these disease groups. RCAN members have identified a set of joint patient-centred recommendations to be included in NCCP for each section on childhood cancers and on rare adult cancers.

Implement dedicated healthcare pathways and mandatory referrals to specialised multidisciplinary Centres of Expertise, or National Networks, and/or European Reference Networks (ERNs)

Implement harmonised preventive measures needed for hereditary cancers/genetic tumour risk syndromes

Support clinical registries developed by expert centres and European Reference Networks (ERNs)

Provide needs-driven supportive care, psychooncology services, and adapted survivorship care planning

Ensure patients, survivors and their families receive the social aid they need. The Right to be Forgotten must be standardised and uniformly implemented

Improve early detection: educate on warning signs, facilitate access to molecular diagnosis, integrate innovative diagnostic technologies

Ensure access to available best treatments, including innovative therapies and clinical trials at national level or in another European country where needed

Develop and support dedicated patient-centred, needs-driven research programmes targeting respectively childhood cancers and rare adult cancers

Support specialised training programmes intended for health professionals and supportive care providers

Promote validated information and training programmes intended for patients, survivors and caregivers

IKCC - International Kidney Cancer Coalition

EU Projects and partnerships

IKCC collaborates with key international and European partners, including WECAN, the Global Cancer Coalition Network, UICC, RBinCT, EAU, and ESMO.

We are also actively involved in several EU-funded initiatives, including Discern, Comfort, and Care1, contributing patient perspectives to improve cancer care across Europe.

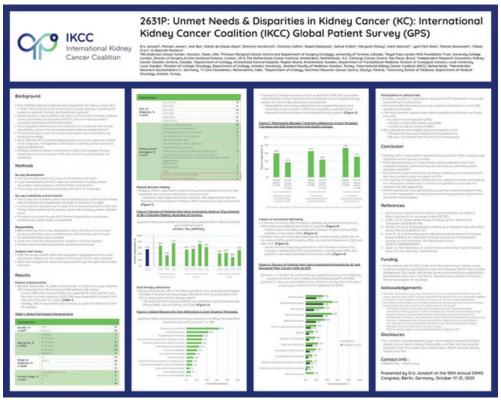
IKCC Flagship Projects

- Global Kidney Cancer Summit
- The Global Patient Survey
- World Kidney Cancer Day
- Education and advocacy tools (infographics, publications, communications, partnerships, collaborations and clinical leadership training)
- Initiatives to advance Shared Decision-Making (SDM) in kidney cancer care.

IKCC Publications 2025

IKCC continued its role as a global leader in patient-focused evidence generation. Key 2025 publications included:

- Updated EAU Guidelines on the Use of Adjuvant Immune Checkpoint Inhibitors and Subsequent Therapy for Renal Cell Carcinoma.
- Impact of postprogression therapies on overall survival: Recommendations from the 2023 kidney cancer association think tank meeting.
- Navigating choices: understanding the decision-making journey of patients with localised kidney cancer.
- EAU Guidelines on Renal Cell Carcinoma: The 2025 Update.
- A Call for a Neoadjuvant Kidney Cancer Consortium: Lessons Learned from Other Cancer Types.
- Neoadjuvant and Adjuvant Immune-based Approach for Renal Cell Carcinoma: Pros, Cons, and Future Directions.
- The impact of the new WHO Classification of renal cell carcinoma on the diagnosis of hereditary leiomyomatosis and renal cell carcinoma..
- Navigating choices: understanding the decision-making journey of patients with localised kidney cancer.



2631P: Unmet Needs & Disparities in Kidney Cancer (KC): International Kidney Cancer Coalition (IKCC) Global Patient Survey (GPS)

IKCC Abstracts

IKCC also published several abstracts & had posters at a number of major events during the year, including: EAU, AUA, EMUC, ESMO, JADPROLive, IKCS & ESMO Asia.

INCA- International Neuroendocrine Cancer Alliance

The **International Neuroendocrine Cancer Alliance (INCA)** achieved significant milestones in 2025, enhancing awareness of neuroendocrine cancer (NENs) and empowering patient advocacy.

NET Cancer Day 2025: Extraordinary Outreach to a Global Audience

NET Cancer Day is held on the 10th of November to increase awareness and provide a voice to the NET community asking for improved diagnostics, treatments, information, care and research. This year's campaign focused on the positive impact of early diagnosis and provision of timely care on NET patient lives. The theme **"Every Stripe Tells a Story"** highlights the importance of early NET diagnosis for the lives of patients and their families.

Campaign assets in 11 languages equipped the NET community and its supporters across the globe to speak in one voice. This campaign reached the largest audience to-date by generating **178.2 million views**.

One Voice Matters. Thousands Create Change: INCA Runs the SCAN 2025 Global Survey

In September 2025, INCA launched the SCAN survey to collect insights and experience from NET patients, caregivers, and healthcare professionals on the state of NET diagnostics, access to treatments and care worldwide.

One Voice Matters. Thousands Create CHANGE.

Help improve care for NET patients.

Take the SCAN 2025 global survey today.

SCAN 2025 is available in 15 languages .

NET Cancer Day

10 November 2025

#LetsTalkAboutNETs #WeScan

SCAN 2025 Global Survey presents two online questionnaires: one for NET patients & caregivers and one for healthcare professionals, available in 15 languages INCA provided SCAN 2025 campaign social media banners in 15 languages to help with the outreach to the NET patient community and healthcare professionals. SCAN 2025 Global Survey was open to respondents from 1st September till 30th November 2025. The survey report is to be published in 2026.

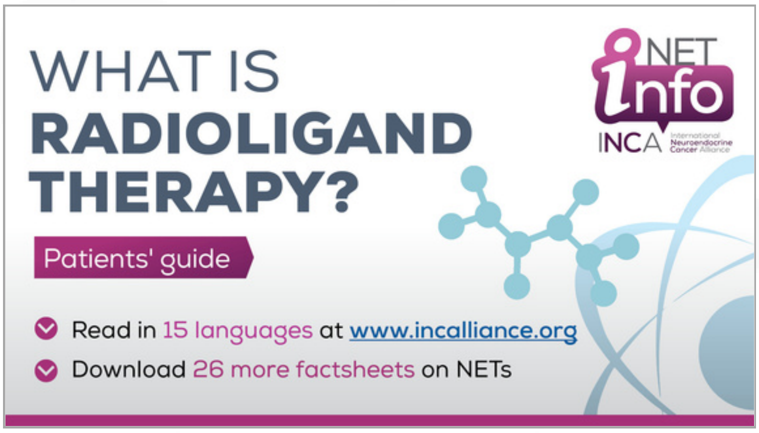
More information: https://incalliance.org/scan2025

INCA- International Neuroendocrine Cancer Alliance

NET Patient Support on Radioligand Therapy

In 2025, INCA added a new valuable resource to its Global NET Patient Information Pack (NETInfo) containing 26 more factsheets on different types of NETs and related syndromes (available in 12 languages). The new factsheet on radioligand therapy was designed to prepare neuroendocrine cancer patients for radioligand therapy.

More information: https://incalliance.org/net-info-packs/



WHAT IS RADIOLIGAND THERAPY?

Patients' guide

- Read in 15 languages at www.incalliance.org
- Download 26 more factsheets on NETs

The Think NENs Global Educational Program for Primary Care Physicians Attracted Graduates from 79 Countries

In late 2024, INCA launched the first global NEN educational program especially designed for primary care physicians. This free CME-accredited e-learning program provides concise knowledge about how to detect neuroendocrine cancer early in general practice. It is available in 7 languages. The program was developed by an international scientific committee representing NEN experts, primary care physicians and NEN patients. In addition, 13 complementary videos on specific NEN topics are available. The program was endorsed by the European Neuroendocrine Tumor Society (ENETS) and by the North American Neuroendocrine Tumor Society (NANETS).

Since its launch till October 2025, the program has attracted and educated approx. 500 healthcare professionals (over 200 are PCPs) from 79 countries.

More information: https://incalliance.org/think-nens/

Think NENs

GLOBAL EDUCATIONAL PROGRAM FOR PRIMARY CARE PHYSICIANS

All you need to know in primary care about neuroendocrine cancer (NEN)

Available in 7 languages

LuCE - Lung Cancer Europe

LuCE's 2025 Projects and Initiatives

Awareness Campaign – Get Supported! (part of the GetChecked! 2021–2025)

- Fifth year of LuCE's GetChecked! awareness campaigns, focussing on the ways to support after a lung cancer diagnosis.
- Based on personal stories from patients and caregivers across Europe.
- New live website to host the campaign.

10th Lung Cancer Europe Report: *"Lung Cancer and Mental Health – Experiences reported by Europeans impacted by lung cancer"*

- Based on the largest global survey on lung cancer and mental health - 2,204 valid responses across 31 countries.
- Translated into 18 languages and launched at ESMO 2025 (Berlin).
- Findings underline the emotional toll of lung cancer and advocate for mental health support as an essential part of care.

Publication of 14 country reports as part of the 9th LuCE Report (2024), with national insights and findings based on the European survey results.

Access to Treatment Atlas:

- Interactive, online tool with data from 30+ countries on access to lung cancer treatments and diagnostics, addressing disparities in lung cancer care across Europe.

Brussels Roundtable – 4 November 2025

- Held with MEP Tomislav Sokol and supported by MEP Andras Kulja, marking LuCE's relaunch of the Call to Action United Against Lung Cancer.

White Paper – At the Crossroads of Tumour-Agnostic Innovation in Europe

- Co-authored by LuCE, it explores how Europe can accelerate access to tumour-agnostic therapies targeting molecular changes across different cancers, including lung cancer.

Policy Brief – Clinical Trials in Europe: Key Trends and Issues

Support of the WHO Resolution on an Integrated Lung Health Approach, adopted at the 78th World Health Assembly in Geneva, reinforcing our commitment to global collaboration in lung health.

LuCE held their **2025 AGM in Berlin** and their **Members' Meeting in Budapest**.

They also attended **several major congresses and WECAN events** including: ELCC 2025 (Paris); EPF Forum 2025 (Brussels); ERS 2025 (Amsterdam); WCLC 2025 (Barcelona); ESMO 2025 (Berlin); WECAN Retreat (Warsaw) & WECAN Academy (Rome).

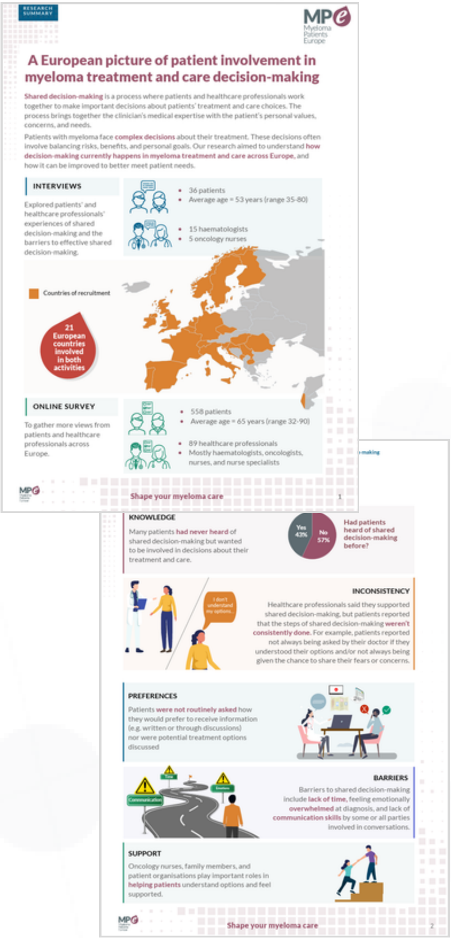
MPE - Myeloma Patients Europe

A key achievement in 2025 was the publication of MPE's research on **shared decision-making in myeloma** and the development of resources to help support patients and their families in making decisions about their treatment and care.

Shared decision-making is a process where **patients and healthcare professionals work together to make important decisions about patients' treatment and care choices**. The process brings together the clinician's medical expertise with the patient's personal values, concerns, and needs.

Patients with myeloma face complex decisions about their treatment. These decisions often involve **balancing risks, benefits, and personal goals**. Our research aimed to understand how decision-making currently happens in myeloma treatment and care across Europe, and how it can be improved to better meet patient needs. Our findings showed that:

1. 57% of patients surveyed had never heard of shared decision-making but wanted to be involved in decisions about their treatment and care.
2. Healthcare professionals said they supported shared decision-making, but patients reported that the steps of shared decision-making weren't consistently done. For example, patients reported not always being asked by their doctor if they understood their options and/or not always being given the chance to share their fears or concerns.
3. Patients were not routinely asked how they would prefer to receive information (e.g. written or through discussions) nor were potential treatment options discussed.
4. Barriers to shared decision-making include lack of time, feeling emotionally overwhelmed at diagnosis, and lack of communication skills by some or all parties involved in conversations.
5. Oncology nurses, family members, and patient organisations play important roles in helping patients understand options and feel supported.



RESEARCH SUMMARY

A European picture of patient involvement in myeloma treatment and care decision-making

Shared decision-making is a process where patients and healthcare professionals work together to make important decisions about patients' treatment and care choices. The process brings together the clinician's medical expertise with the patient's personal values, concerns, and needs.

Patients with myeloma face **complex decisions** about their treatment. These decisions often involve balancing risks, benefits, and personal goals. Our research aimed to understand **how decision-making currently happens in myeloma treatment and care across Europe**, and how it can be improved to better meet patient needs.

INTERVIEWS

Explored patients' and healthcare professionals' experiences of shared decision-making and the barriers to effective shared decision-making.

- 36 patients
- Average age = 53 years (range 35-80)

- 15 haematologists
- 5 oncology nurses

ONLINE SURVEY

To gather more views from patients and healthcare professionals across Europe.

- 558 patients
- Average age = 65 years (range 32-90)

- 89 healthcare professionals
- Mostly haematologists, oncologists, nurses, and nurse specialists

Shape your myeloma care 1

KNOWLEDGE

Many patients **had never heard** of shared decision-making but wanted to be involved in decisions about their treatment and care.

INCONSISTENCY

Healthcare professionals said they supported shared decision-making, but patients reported that the steps of shared decision-making **weren't consistently done.** For example, patients reported not always being asked by their doctor if they understood their options and/or not always being given the chance to share their fears or concerns.

PREFERENCES

Patients **were not routinely asked** how they would prefer to receive information (e.g. written or through discussions) nor were potential treatment options discussed

BARRIERS

Barriers to shared decision-making include **lack of time,** feeling emotionally **overwhelmed** at diagnosis, and lack of **communication skills** by some or all parties involved in conversations.

SUPPORT

Oncology nurses, family members, and patient organisations play important roles in **helping patients** understand options and feel supported.

Shape your myeloma care 2

As a first step to help raise awareness around shared decision-making, MPE created this **educational video**, which was shared widely as part of European Myeloma Day in September. In the coming year, MPE will develop additional resources to educate and support the patient community.

SPAGN - Sarcoma Patient Advocacy Global Network

2025 Projects

- **Global Sarcoma Diagnosis Pathway Survey**: Aim was to gather valuable data directly from sarcoma patients and caregivers worldwide, to better understand the patient experience in receiving a timely and correct diagnosis. We have received about 1.800 responses. The results have been presented at ESMO and CTOS. A publication will be submitted.

- **Patient-Powered Research Network:** Priority Setting Partnership (PSP) to identify key research and advocacy priorities in sarcoma care to help steer future research, aid funding agencies in project assessment, and strengthen the role of patient advocates in representing our community's needs.
- **Sarcomunicándonos América Latina**: Outreach Program for Latin America (ES/PT).
- **Sarcoma Intelligence Specialist Networks**: Identify features and principles for optimal sarcoma management and an appropriate term for a system ("specialist intelligent network") that could be applied across the world. Published 2024 in peer-reviewed magazine.

- **Consensus Papers**: collaboration of patients, patient advocates and experts to address specific topics/subtypes. E.g. "*Best clinical management in TGCT*" or "*Current Management of Desmoid Tumors*".
- **Bone Sarcoma Alliance**: Informal partnership initiative, composed of bone sarcoma patient groups, patient/parent advocates and patient networks to work on areas of common concern.
- **Annual Advocacy in Action Award**: best practice examples of national patient advocacy organisations. The aim is to elevate and recognise exceptional initiatives, projects, campaigns, and the dedicated individuals steering these efforts.
- **Blog "Voices of Sarcoma"**: Covers topics of interest to the wider SPAGN community, in order to convey information, share experiences and viewpoints, and strengthen the bonds of the international sarcoma community.
- Participation/lead of scientific publications in peer-reviewed magazines.

SPAGN held and attended a number of event during the year, including the **15th SPAGN Annual Conference** 2025 in Washington D.C., CTOS 2025, ESMO Sarcoma & Rare Cancers & EMSOS.

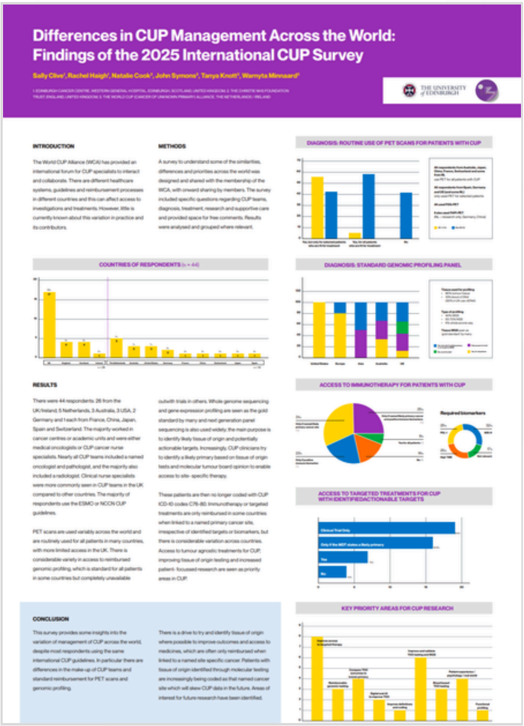
WCA - World Cup Alliance

In 2025, the **World Cup Awareness (WCA)** organisation achieved major milestones in advancing awareness and improving care for **Cancer of Unknown Primary (CUP)**.

- **2 new CUP patient organisations** have joined our alliance: CUP-Forum from Germany and Rock4Life from France.
- Hosted our first **International CUP Meeting** in Berlin on October 16th. For the first time, **180 CUP specialists** (i.e., clinicians such as oncologists, pathologists, radiologists, researchers & advocates) from 29 countries and 5 continents came together, with proceedings from meeting having been accepted for publication in a journal in 2026.
- We **launched a new patient leaflet** in co-creation with Clatterbridge Cancer Centre, Peter MacCallum Cancer Centre and Deakin University Melbourne where patients and their caregivers are encouraged to think about what questions and concerns they want to raise with their doctor, it can be downloaded via: *WCA_YourThoughtsMatter_Digital A4.*
- Our founding member SJK is one of the charity partners in a **€28 million cancer precision oncology research funding** in Ireland
- Our founding member MTO has been a one of key partners in getting the **new 2025 clinical CUP guidelines** published in the Netherlands: *Startpagina - Primaire tumor onbekend - Richtlijn - Richtlijnendatabase*

The World CUP Alliance was active at a number of events and congresses during the year, including ESMO 2025, National CUP Symposiums, IQN Path and the AstraZeneca PALs Summit.

- The World CUP Alliance has **co-created a survey together with Dr. Sally Clive from Edinburgh Cancer Centre to understand variation in CUP practices, treatments and diagnostics** as different countries operate with different healthcare systems, use different guidelines and reimbursement processes. Little was currently known about this variation in practice and priorities in CUP care, hence we created the survey and shared this via our platform. The survey included specific questions regarding CUP teams, diagnosis, treatment, research and supportive care and provided space for free comments. Results were analysed and grouped where relevant, and a poster developed.



Differences in CUP Management Across the World: Findings of the 2025 International CUP Survey

Sally Clive[1], Rachel Haigh[1], Natalie Cook[2], John Symons[3], Tanya Knott[3], Warnyta Minnaard[3]

INTRODUCTION

The World CUP Alliance (WCA) has provided an international forum for CUP specialists to interact and collaborate. There are different healthcare systems, guidelines and reimbursement processes in different countries and this can affect access to investigations and treatments. However, little is currently known about this variation in practice and its contributors.

METHODS

A survey to understand some of the similarities, differences and priorities across the world was designed and shared with the membership of the WCA, with onward sharing by members. The survey included specific questions regarding CUP teams, diagnosis, treatment, research and supportive care and provided space for free comments. Results were analysed and grouped where relevant.

RESULTS

CONCLUSION

Annual Accounts 2025

Income	
Income Received	€803,200
Academy 2025	€410,000
EuroACT	€240,000
PED	€92,800
Cancer Survey	€60,400
Income committed pending to receive	€110,600
Deferred Income	€406,929
Total income	**€1,320,729**

Expense	
Academy 2025	€281,864
Academy 2026	€13,626
ESMO	€7,755
EuroACT Phase III+V	€262,374
EuroACT Phase V committed	€138,943
PED	€20,114
PED Committed	€70,573
Cancer Survey Phase I	€23,549
Cancer Survey Committed Phase I & II	€147,763
Secretariat	€187,779
Total expense	**€1,154,340**
Result	€166,389

Industry Partners 2025

We greatly appreciate your support for WECAN's 2025 programmes and initiatives:

abbvie
AMGEN
AstraZeneca
Boehringer Ingelheim
Daiichi-Sankyo
GILEAD
Incyte
IPSEN Innovation for patient care
Jazz Pharmaceuticals
Johnson&Johnson
Lilly
MERCK
MSD
NOVARTIS
Pfizer
Roche
sanofi
SERVIER*
Takeda

Thank You!

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

References

WECAN AFFILIATE 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/

Lymphoma Coalition
http://www.lymphomacoalition.org/

MDS Alliance
https://www.mds-alliance.org/

Melanoma Patients Network Europe
https://www.mpneurope.org/

MPN Advocates Network
https://www.mpn-advocates.net/

Myeloma Patients Europe
https://www.mpeurope.org/

Pancreatic Cancer Europe Network
http://www.pancreaticcancereurope.eu/

Sarcoma Patient Advocacy Global Network
http://www.sarcoma-patients.eu/en/

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

RESEARCH

Cases, Mercè and Imre, Attila and Giles, Rachel H. and Puga, Lis and Piggin, Maria and Geissler, Jan and Racovita, Monica and Leto di Priolo, Susanna and Wogu, Lora Ruth and Hyseni-Bocolli, Albina and Morgan, Kate and Hosszú, Dalma and Józwiák, Ákos and Ágh, Tamás and Plate, Ananda and Group, EuroACT Working, Geographic Inequities in Patient-Reported Outcome Measures in Clinical Trials of Selected Solid Tumours in Europe: Findings from EuroACT. http://dx.doi.org/10.2139/ssrn.5390471

Cases, Mercè and Imre, Attila and Giles, Rachel H. and Puga, Lis and Piggin, Maria and Geissler, Jan and Racovita, Monica and Leto di Priolo, Susanna and Wogu, Lora Ruth and Hyseni-Bocolli, Albina and Morgan, Kate and Hosszú, Dalma and Pitter, János György and Ágh, Tamás and Plate, Ananda, Variation in Use of Patient-Reported Outcome Measures and in Geographical Distribution in Clinical Trials of Selected Malignant and Non-Malignant Haematological Diseases in Europe: Findings from EuroACT. http://dx.doi.org/10.2139/ssrn.5646744

Cases M, Giles R, Ágh T, Piggin M, Geissler J, Racovita M, Hagymásy J, Ruth Wogu L, Józwiak Á, Hyseni-Bocolli A, Hosszú D and Plate A (2025) Methodological study protocol for The European Atlas of clinical trials in cancer and haematology. https://doi.org/10.3389/fphar.2025.1558556

WECAN

2025 ACTIVITY REPORT: A YEAR IN REVIEW

WECAN
Foundation

Info@wecanadvocate.eu
www.wecanadvocate.eu
Academy.wecanadvocate.eu