

ANNUAL NEWSLETTER #2



Welcome to the second issue of the annual newsletter of the EU PAL-COPD project! Join us and explore more about our journey so far.

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PROJECT INSIGHTS

EU PAL-COPD: 2025 – A Year of Strong Progress and Collaborative Momentum

Over the course of 2025, EU PAL-COPD has made substantial strides in preparing for the evaluation and implementation of the ICLEAR-EU intervention across six European countries. Thanks to the dedication of clinical teams, researchers and partners from all work packages, the project has moved from preparation and adaptation into full implementation readiness, and the stepped-wedge trial study is now underway.

Completion of ICLEAR-EU Adaptation

During the first half of the year, our consortium completed the adaptation and standardisation of the ICLEAR-EU intervention. Local Adaptation Teams composed of clinicians and researchers in each country, supported by an international oversight group and patient representatives, worked intensively to ensure the intervention reflects the cultural and organisational realities of each health system while maintaining its core components.



Early 2025 also marked the completion of the multi-country small-scale pilot testing. Multidisciplinary hospital teams across Europe piloted the ICLEAR-EU intervention with patients and caregivers. Their experiences and feedback provided critical insights that strengthened the final version of the clinical manual and informed refinements to training, study procedures and implementation strategies. During the pilot study, researchers also tested the data collection methods with patients and caregivers, ensuring that data collection in the stepped-wedge trial study will be both comprehensive and feasible.

Finalising Training and Materials

Alongside this, the training programme for clinical teams was finalised, including a comprehensive e-learning module and in-person sessions to prepare respiratory and palliative care teams for the roll-out of ICLEAR-EU. Trainers and experts from several countries contributed to shaping materials that are now ready for deployment at all trial sites. Supporting the train-the-trainer model, trainers from the scientific partner countries attended a live

preparatory session in November, led by LAN.

Preparing for the Stepped-Wedge Trial

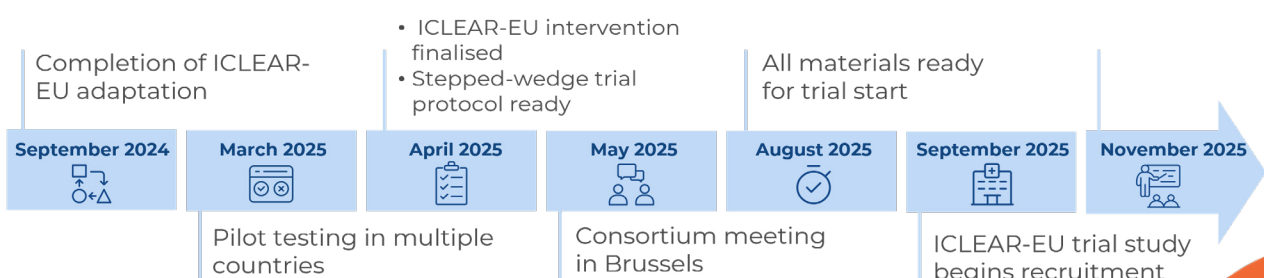
Significant progress was also achieved in the development of the clinical trial infrastructure. Partners collaborated to finalise the protocol, align ethics and governance processes, and prepare hospital sites for the stepped-wedge trial. Data management systems were established, ensuring secure, harmonised data collection across countries. Project coordination structures continued to support smooth collaboration, with regular

consortium-wide meetings, scientific advisory guidance, and efficient management of reporting, communication and risk monitoring. This collective effort has positioned EU PAL-COPD to move confidently into the next phase of implementation.

As we look ahead, 2025 stands as a year marked by progress, teamwork and shared commitment—bringing us one step closer to improving palliative care integration for people living with advanced COPD and their families across Europe.



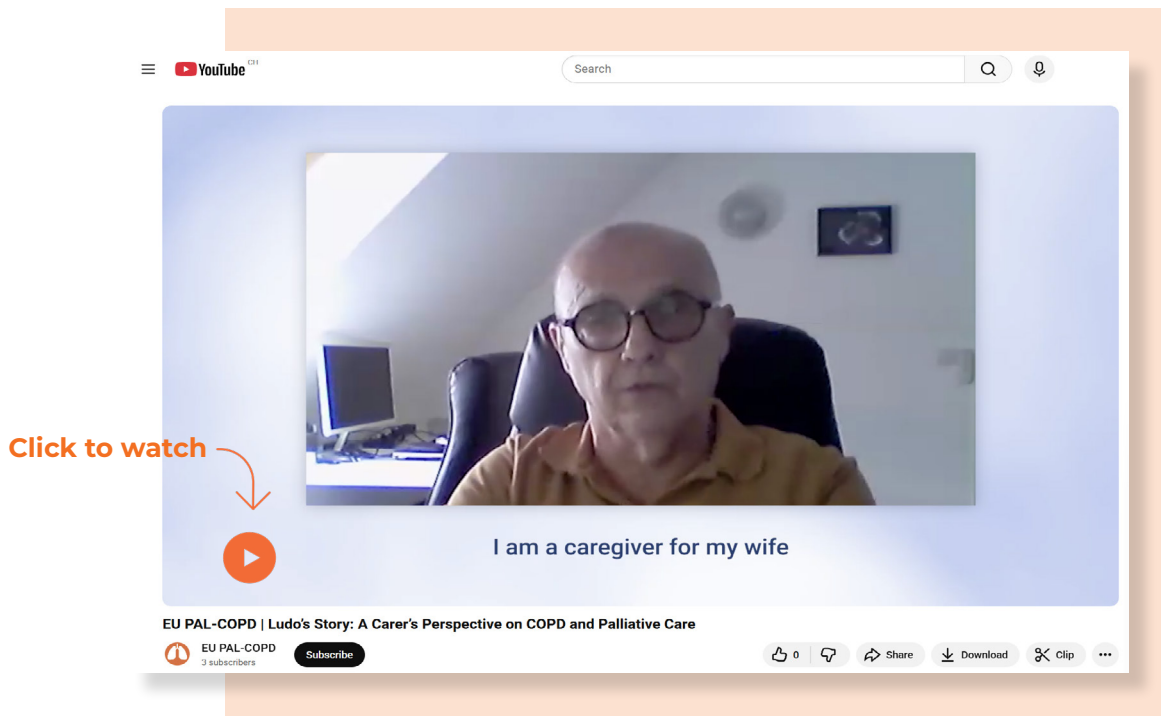
EU PAL-COPD in 2025



PATIENT PERSPECTIVE

Amplifying the Voice of a Carer – Ludo's Story

This year, EU PAL-COPD continued to place [video featuring Ludo](#), who shares his personal lived experience at the heart of the project. To mark World COPD Day 2025, we released a new



In the video, Ludo reflects on how COPD has shaped daily family life, the value of joining a patient support group, and why early, integrated palliative care can make a meaningful difference for both patients and those who support them. His insights highlight the emotional, practical and social dimensions of caregiving—perspectives that are often missing from traditional healthcare discussions.

Ludo is a member of the European Lung Foundation's COPD Patient Advisory Group (PAG). Throughout 2025, the PAG continued to play an essential role in EU PAL-COPD, contributing to consultations,

reviewing project materials and ensuring that the voices of people directly affected by COPD guide our work and its outcomes.

Sharing real stories like Ludo's is a key part of our mission to raise awareness and promote understanding of palliative care in COPD.

If you are interested in joining the ELF COPD PAG and getting involved in research projects like EU PAL COPD and others, please get in touch with us
<https://europeanlung.org/en/contact-us/>

EU PAL-COPD AT EVENTS

In 2025, EU PAL-COPD was strongly represented at two major international congresses through the active involvement of our consortium partners ERS and EAPC, helping raise awareness of the project and strengthen connections across the respiratory and palliative care communities.

EAPC World Congress 2025

Earlier in the year, EU PAL-COPD was presented at the [19th World Congress of the European Association for Palliative Care](#) (EAPC) in Helsinki. Partners from Lancaster University and VUB showcased research on adapting the ICLEAR palliative care model

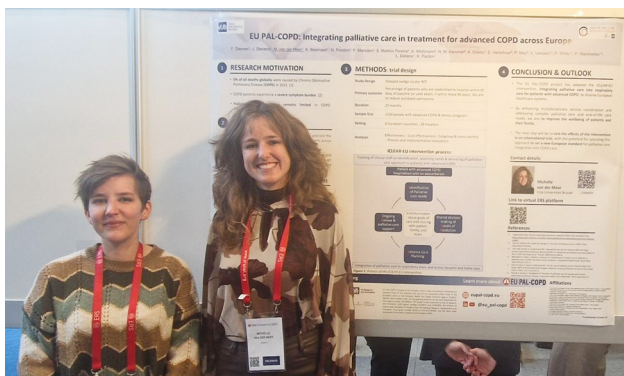
across European contexts and establishing an international patient and public involvement group. EU PAL-COPD also gained visibility through the EU Projects session and materials distributed at the EAPC stand, engaging a wide audience of palliative care professionals.



ERS International Congress 2025

At the [ERS International Congress 2025](#), the EU PAL-COPD team hosted an international meeting where speakers from the Philippines, Turkey and Georgia presented their perspectives on palliative care in COPD, and Dr. Paul Marsden shared the UK ICLEAR model.

The consortium also presented its poster, delivered by Michelle van der Meer, which drew strong interest from delegates. Ahead of the Congress, a survey circulated to ERS members received 123 responses, helping broaden awareness and engagement with the project.



THE FOUR PHD STUDENTS BEHIND THE EU PAL-COPD PROJECT



**Mannon
Wubbels**

Radboudumc, NL



**Marie Van de
Walle**

Ghent University, BE



**Michelle van
der Meer**

VUB, BE



**Mishka
Beutels**

VUB, BE

Manon, Marie, Michelle, and Mishka are four PhD students within the large international EU PAL-COPD consortium. Having different backgrounds in clinical orthopedagogy, biomedical sciences, and experimental psychology and being affiliated with three different universities enrich their collaboration. Besides, they span more than a decade in age, which adds a valuable mix of experience, perspectives, and ideas. This diversity determined their research topics. Manon will focus on the process implementation and evaluation, Marie is interested in indicators of hospital (re)admissions, Michelle will discover family caregivers' perspectives and communication between clinicians, while Mishka will enrich knowledge about the existential and spiritual domain in palliative care.

Despite the variety between them, they share one common goal (and the letter of their first name): obtaining their PhD within this project. To do so, they collaborate on ethical committee applications, coordinating and monitoring tasks, data collection with patients and family caregivers, and maintaining contact with the hospitals. They carry out these tasks in close coordination with their supervisors, the consortium, and with each other.

One unifying thread brought them together in this project: collaboration. They highly value the international partnerships within the consortium, meaningful communication with patients and family caregivers, exchanging ideas with hospital clinicians, attending conferences (they always coordinate who goes where), and exploring cultural differences in healthcare contexts. It's no coincidence that they are part of a project where communication and collaboration are central. Sharing the same language (despite four totally different accents) makes it easy to share experiences of this learning journey.

For all four of them, there will be a lot of "firsts" within this project. Their first data collection with COPD-patients and family caregivers, their first interviews with respiratory clinicians, their first paper as a first author, or their first conference presentation. However, the focus is not on these outcomes, but on the process towards these.

They aim for ongoing collaboration among themselves and within the broader consortium. They hope to continue supporting each other within this project, but also within the more individual trajectories of their PhD. And one final note: be cautious when asking a PhD about plans after the PhD. To be honest, they have no idea yet, and they enjoy the position they are currently in!

FROM DATA TO ACTION: HOW THE EAPC ATLAS SUPPORTS EU PAL-COPD'S MISSION

Click to read



During the 19th World Congress of the European Association for Palliative Care (EAPC) in Helsinki, the association launched the EAPC Atlas of Palliative Care in the European Region 2025. The creation of this Atlas, marks a major milestone in mapping the current state of palliative care throughout Europe. Published by the Global Palliative Care Observatory ATLANTES, University of Navarra and the EAPC, the Atlas offers a detailed and contemporary overview of the development of palliative care in 56 countries. The Atlas captures data on access to essential medicines, education, research, national policies, as well as service distributions from these countries, presenting a valuable evidence base for researchers, clinicians, and policymakers.

EAPC Atlas can also be utilised as both a guide and benchmarking for the EU PAL-COPD project, which is aiming to integrate palliative care and

respiratory medicine for patients with advanced COPD. The Atlas will enable the consortium of the project, to recognise the broader context of palliative care sector, and identify where integration within respiratory care is most advanced or still underdeveloped in the European region.

In addition to that, the Atlas will also support researchers to identify gaps, aligning methodologies, and maximise existing strengths within contributed countries, by providing detailed, comparable indicators and insights. Not only for the researchers, educators, clinicians and healthcare planners can also use information from the Atlas to benchmark their services, design training priorities, and create recommendations to policymakers in how to improve patient-centered care in their countries.

As EU PAL-COPD project continues its work to ensure that people with advanced COPD receive timely, high-quality palliative care, the insights from the EAPC Atlas will help converting data into action, supporting evidence-based strategies that strengthen care systems and improve quality of life for patients and their families.

Click the link and get the full access to the [Atlas](#).

EU PAL-COPD: Next Steps

As the project enters 2026, the **stepped-wedge trial testing the ICLEAR-EU intervention approaches its first transition point. The start of the first intervention wedge will be a major milestone in the trial.** In each of the six countries, one of three hospitals will cross over from providing care as usual, to implementing ICLEAR-EU. During the transition month in February, clinical teams will be trained and supported to start providing the intervention, with close monitoring to ensure optimal implementation. The consortium will continue its close collaboration internally and with independent experts to track recruitment to the trial, ensuring quick and effective adjustments can be made to consistently reach our six-monthly targets.

The EU PAL-COPD consortium will also continue to uphold its commitment to dissemination and communication with clinicians, patients, researchers, and the public, while sharing the findings in scientific publications.

Useful resources

- [**Literature Collection**](#)

Our Literature page brings together key publications, reports and scientific resources in palliative and respiratory care that inform and support the EU PAL-COPD project.

- [**Video Interviews**](#)

Watch interviews with EU PAL-COPD partners who share their perspectives, expertise and involvement in the project, offering an inside look at the people driving our work forward.

- [**Media Corner**](#)

Explore our Media Corner for printable materials, project visuals and platforms that introduce EU PAL-COPD and explain our work to patients, professionals and the public.

- [**EU PAL-COPD blog: Behind the Scenes**](#)

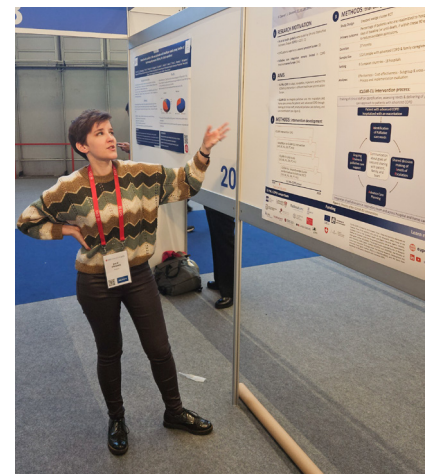
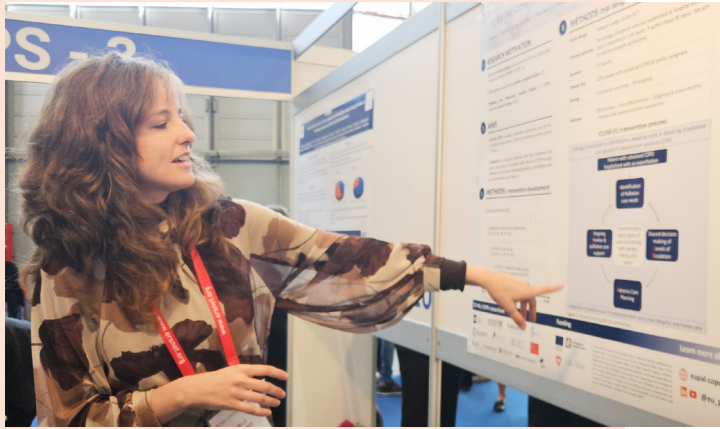
- [**Blog 1 | Blog 2**](#)

Discover how our project partners work together across countries and disciplines in this blog series showcasing team stories, collaboration highlights and insights from inside the consortium.

- [**EU PAL-COPD Clinical Trial Registration on ISRCTN**](#)

The EU PAL-COPD clinical trial is now officially registered on the ISRCTN registry and you can view the public trial record by clicking the link above.

GALLERY



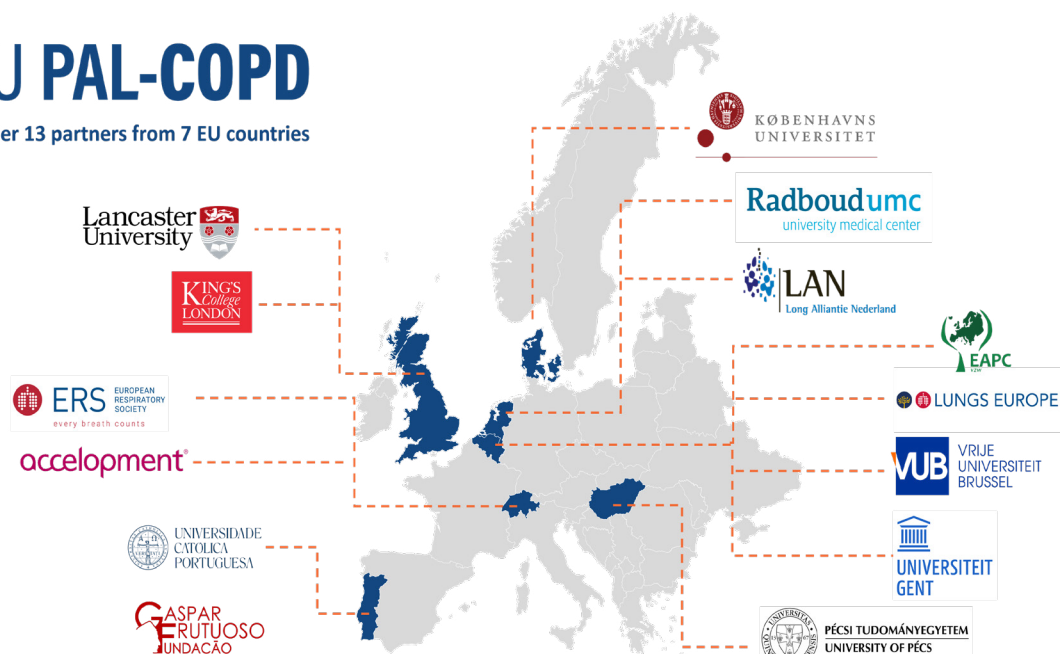
Stay connected

Stay informed about the EU PAL-COPD project with our newsletter, which goes beyond project updates:

- The most recent developments in the field of palliative and respiratory care from the EU PAL-COPD partners.
- Valuable insights and expert opinions from our partners.
- A community of like-minded individuals promoting collaboration and knowledge sharing.
- Potential opportunities for partnerships and collaborations.
- Exclusive interviews with members of our consortium and representatives of our Patient Advisory Group.

Get in touch

Are you interested in collaboration with EU PAL-COPD? Or simply want to know more about the project? Visit our website for more information, follow us on social media or contact us via email:



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PROJECT
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