

# ANNUAL NEWSLETTER #1



Welcome to the first 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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# HELLO & WELCOME

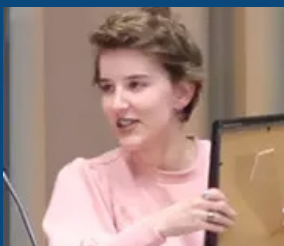
## Message from the coordinating team



**Luc Deliens**  
Project Co-coordinator



**Koen Pardon**  
Project Co-coordinator



**Julie Stevens**  
Coordinating Team  
member



**Frederick Daenen**  
Coordinating Team  
member

### Dear reader,

It is our great pleasure to welcome you to the first edition of the EU PAL-COPD newsletter.

Between the start of the project on January 1st 2024 and today, the EU PAL-COPD consortium has already made great strides towards our aim of introducing an integrated palliative care approach for people with advanced chronic obstructive pulmonary disease (COPD). A productive kickoff meeting in Brussels set the tone for the months to follow: 13 partners across 7 countries have shown their engagement and dedication, bringing their expertise and skills to the table as we prepare for the international randomised trial set to begin in the summer of 2025.

The value and scope of this preparation are not to be underestimated. The promising UK-based model of the ICLEAR intervention was the basis of our intervention manual, which has now been culturally adapted based on participatory consultations with stakeholders and discussions with our International Adaptation Oversight Group. Adding to this a thorough translation process of questionnaires by our international partners, and training prepared both for our research staff and for clinicians, the next step of the project is underway as we write this foreword: pilot testing the adapted intervention, questionnaires, and data collection across Belgium, the Netherlands, the UK, Denmark, Portugal, and Hungary. These steps will ensure we are ready for our ambitious international trial.

Throughout these months, the EU PAL-COPD consortium has laid the foundations for strong working relationships, structured collaboration, and efficiency combined with flexibility. We look forward to continuing on this path to ensuring timely integrated palliative care for people with advanced COPD, and invite you to read on about what this project has already achieved.

Sincerely,  
VUB coordinating team

# ABOUT EU PAL-COPD

## Problem: Implementing Comprehensive Palliative Care for patients with COPD in Europe

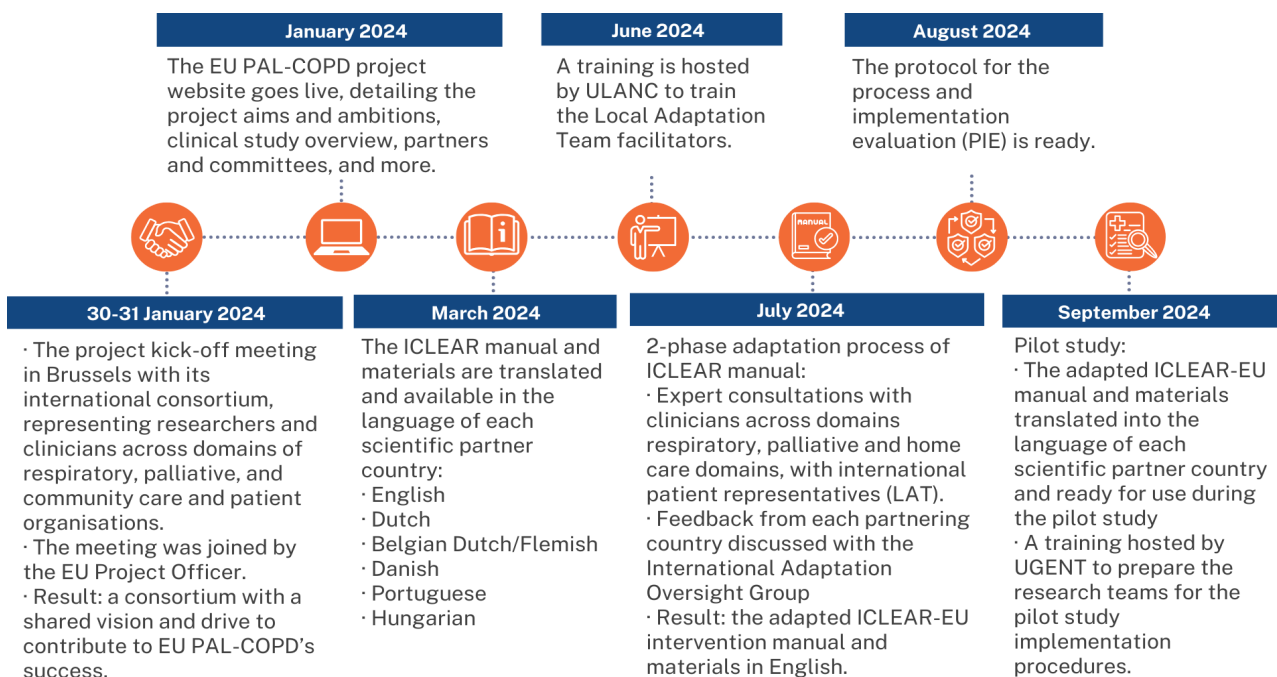
Patients with COPD in European countries are still receiving inadequate and delayed palliative care despite experiencing high symptom burden. The prognostic uncertainty which characterises COPD means that conversations about future care are often not initiated by health care professionals and that palliative care is too often provided only in the final weeks or days, failing to deliver the comprehensive and supportive care patients and their families need.

Integrating palliative care into standard respiratory care for people with COPD has been shown to reduce exacerbations and unplanned hospital admissions, whilst improving quality of life of both patients and their families.

## Solution: EU PAL-COPD – A European Initiative to Integrate Palliative Care and Respiratory Medicine

The EU PAL-COPD project is a collaborative effort among researchers, clinicians, health economists and patient organisations to improve the care of individuals with advanced COPD. The project launched in January 2024 and has made significant progress in the following months. All of these developments are laying the foundation for the ultimate goal of EU PAL-COPD: the implementation of a new non-pharmacological intervention that integrates palliative and respiratory care for patients with COPD in Europe..

## EU PAL-COPD Milestones in 2024



# PATIENT PERSPECTIVE

## An Interview with our Patient Representative, Irene

Earlier this month, we spoke with Irene, a patient representative in EU PAL-COPD and a member of the [European Lung Foundation](#) COPD Patient Advisory Board. She told us about how she became involved in the project and why it is important to her.

### Could you please tell us a little bit about yourself?

My name is Irene, I'm 77 years old and I come from the East of England. I have a master's degree in social research methodology. I worked as a Service Manager in social work in childcare and child protection. When I retired, I worked in the research arm of our NHS as a patient reviewer of health research for 15 years. In the early days this was difficult as there was a reluctance for patients to be involved but now this has been resolved and for the most part patients' views are seen as integral to research.

### How did you get involved with the EU PAL-COPD project?

I personally knew a researcher from Lancaster University in the UK, who is involved in the EU-PAL COPD project. 18 months ago, when I found out about my condition, she invited me to join the project as a patient to help bring the patient voice to research.

### How have you engaged in the project so far?

It feels like the project is in its early stages, so at first, we are just sharing our experiences about COPD. So far, we have attended 2 meetings with researchers where we could say what was important to us as COPD patients. I felt that our opinion mattered a lot, because in the early days of my career as a patient engagement specialist I learned to see when patients are not taken seriously. This is not the case here.



### Why are you interested in this project?

Firstly, I am a patient myself. Secondly, as the project has a global reach, I was interested to learn about the many similarities in different European countries, although not all the services are the same. The project can help us learn from each other's experience and improve palliative care for COPD patients from different countries.

### The project is about quite a sensitive topic – how do you personally feel about participating in it?

I think that as a patient in this project you have to be dispassionate because it is not about you and it's not about answering questions about your health. It is more about the experience you can share with the research to help patients with similar conditions.

**Was there anything challenging/difficult about participating in the project?**

I would say that it is difficult for me to hear the stories of people who are struggling. It's also upsetting when I know that someone's condition is close to mine - but I try to separate myself from it.

**There were many different people from all over Europe at the meetings - how was it?**

I am interested to hear about their experiences. It's nice to find similarities in different contexts. Patients suffer from the same problems with medicines in different healthcare systems. For example, now I can compare our healthcare system, which I consider to be somewhat paternalistic, with the Belgian one, which I have heard is more liberal.

**What do you hope happens in the future as a result of this project?**

As we look at palliative care for COPD patients, I hope that we can integrate it as part of COPD treatment for those patients who need it. I hope this project will help them make the right choice if they want palliative care. There is so much uncertainty for people with this disease, but making an informed decision about their treatment is something that every patient should have the right to do. I haven't made a decision yet myself, but I hope that participating in this project will also help me decide what is best for me.

**Why it is important that patients are involved in projects like this? What do patients bring to research?**

I believe that patients have a say and have a unique perspective based on the experiences we have every day. When we represent different countries, we can share best practices in treatment to contribute to the idea of the most appropriate form of care.

**Is there anything you would like to add?**

For me, in general, participating in the project is very exciting because I like to see other patients, it's interesting to hear stories about how similar we are in what we are going through. I especially like working with the researchers. I have a friend in the research team who I respect and trust, and I can talk freely about my condition and how I feel.

If you are interested in joining the ELF COPD Patient Advisory Group and getting involved in research projects like EU PAL COPD and others, please get in touch with us

<https://europeanlung.org/en/contact-us/>

## ICLEAR-EU TRAINING TO IMPROVE PALLIATIVE CARE FOR PATIENTS WITH COPD IN EUROPE



**Els Verschuur**

WP3 Training development and implementation guidance Lead

Senior project manager  
Palliative care in COPD  
Lung Alliance Netherlands

How can we make palliative care better for people with COPD? That's the key question the EU PAL-COPD project is tackling with the ICLEAR-EU intervention. A big part of this effort is the ICLEAR-EU Training, which includes two main components:

- an online learning module
- a hands-on training on how to use the ICLEAR-EU intervention in everyday care

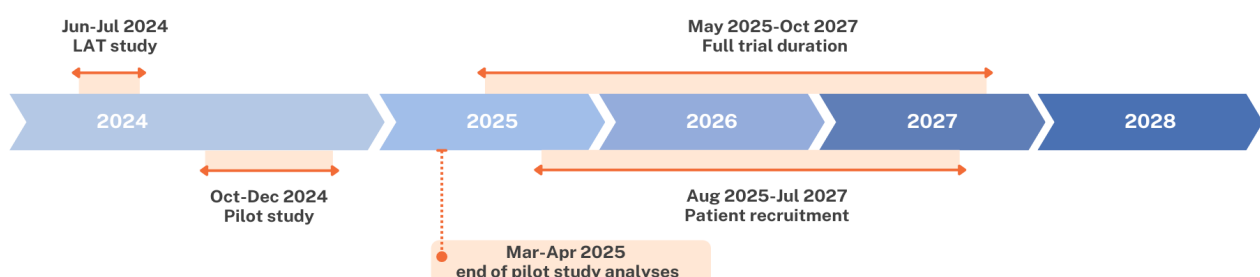
Led by Els Verschuur from Lung Alliance Netherlands, the training aims to help healthcare professionals from 18 hospitals across 6 European countries. The focus? Learning to apply ICLEAR-EU during weekly meetings where a multidisciplinary team of healthcare professionals discusses the care of COPD patients with palliative care needs. The training revolves around Tina and John, a retired couple dealing with the challenges of advanced COPD.

Each country has one or two trainers experienced in palliative care for COPD, teaching, and implementation. These trainers will help roll out the training in the feasibility study, running October to December 2024. As part of this, we have developed feedback forms to gather their experiences and thoughts. This feedback will shape the final version of the training, which will be used in the Randomised Controlled Trial (RCT) in 2025.

In the end, everything learned from the RCT will be added to the final ICLEAR-EU Training, ensuring the training continues to benefit healthcare professionals long after the EU PAL-COPD project ends.



## PRIOR TO THE ICLEAR EU TRIAL: LOCAL ADAPTATION TEAMS (LAT) STUDY AND PILOT STUDY



## NEW FACES



**Michelle van der Meer**

Doctoral researcher at Vrije  
Universiteit Brussel (Belgium)

“ I’m passionate about working on a European project that focuses on integrating palliative care into the standard care of patients with advanced COPD, as it aligns with my belief in compassionate, patient-centered care. Understanding the daily challenges these patients face, I believe that good palliative care is essential for improving their quality of life. Contributing to a project that aims to enhance this care across Europe feels very meaningful to me, as it provides an opportunity to make a real impact in supporting both patients and their families.



**Marie Van de Walle**

PhD student at Ghent  
University (Belgium)

“ Joining the EU PAL-COPD team allows me to contribute to meaningful changes in standardized care for COPD patients across Europe. I am excited to apply my passion for improving quality of life, ensuring that patients receive the personalized care they deserve. At the same time, I am eager to learn new research skills and gain valuable insights in health care.



**Laure Dombrecht**

Postdoctoral researcher at  
Ghent University (Belgium)

“ The EU PAL-COPD project will address palliative care needs for COPD patients on an international level, which is much needed for patients and their immediate family. I hope to contribute to the project with my experience in qualitative and quantitative data-analysis, and insights in complex hospital interventions for vulnerable groups.

## IDENTIFYING COLLABORATIONS: SIMILAR INITIATIVES

EU PAL-COPD is dedicated to advancing palliative care alongside several other projects funded by the European Commission. The following projects were selected under the same call topic “Novel approaches for palliative and end-of-life care for non-cancer patients”.



**PsyPal** is a Horizon Europe project seeking to explore whether psilocybin therapy (also known as psilocybin-assisted therapy/treatment or psilocybin with psychotherapeutic support) in palliative care settings may help to alleviate experiences of existential distress for individuals with COPD as well as patients with the neurological conditions multiple sclerosis, amyotrophic lateral sclerosis and atypical Parkinson's disease.

**PALLIAKID** is a project aiming to evaluate the feasibility, effectiveness, and cost-effectiveness of novel interventions for children, adolescents and young people with palliative and end-of-life care needs in different healthcare systems across Europe, with a focus on those factors that influences the active patients' and family caregivers' engagement.



The **EPIC** project aims to sustainably improve palliative care for critically ill patients and their families in the ICU. An interdisciplinary consortium collaborates to provide a novel harmonised palliative care practice model using telemedicine. The project is the first European interventional study on palliative care in the ICU, using a systems-based approach with proactive patient identification, checklist and blended learning targeted to specific requirements of ICU clinicians.

The **RAPHAEL** consortium sets out to integrate the RAPHAEL palliative care approach in existing heart failure care pathways. This flexible and patient centred approach starts with the identification of multidimensional symptoms and concerns, prioritise needs with patient and informal carer and formulate a proactive care plan. The symptoms and concerns will be monitored by the patient at home using the PAL@HEART app. The app can be used to evaluate interventions, support communication and early identify new or increasing needs.



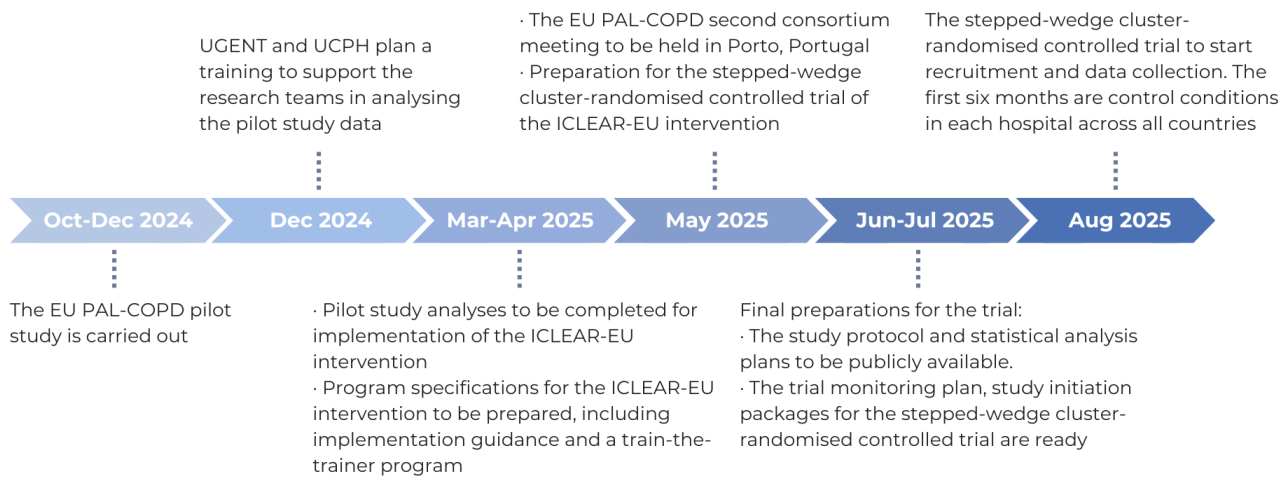


# GALLERY



# EU PAL-COPD: Next Steps

In 2025, EU PAL-COPD is set to accomplish several major milestones, including the roll-out of the stepped-wedge cluster-randomised controlled trial. This trial and the data collected are crucial in ensuring that the ICLEAR-EU intervention can be successfully rolled out across hospitals in different countries delivering care to patients with advanced COPD as per local standards of best practice.



## Useful Resources



ERS Clinical Practice Guideline: Palliative care for people with chronic obstructive pulmonary disease or interstitial lung disease:

[Publication](#)

[Additional material](#) (webinar, video, slides kit, pocket guide, congress session):

European Respiratory Society Clinical Practice Guideline on symptom management for adults with serious respiratory illness:

- [Publication](#)
- [Video 1](#), [Video 2](#)
- [Online learning module](#): Palliative care in chronic respiratory disease



- [Palliative oxygen therapy](#)
- [Rehabilitation in palliative care](#)
- [Education training in palliative care](#)
- [Family Carer - EAPC](#)

# 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:

 [eupal-copd.eu](http://eupal-copd.eu)

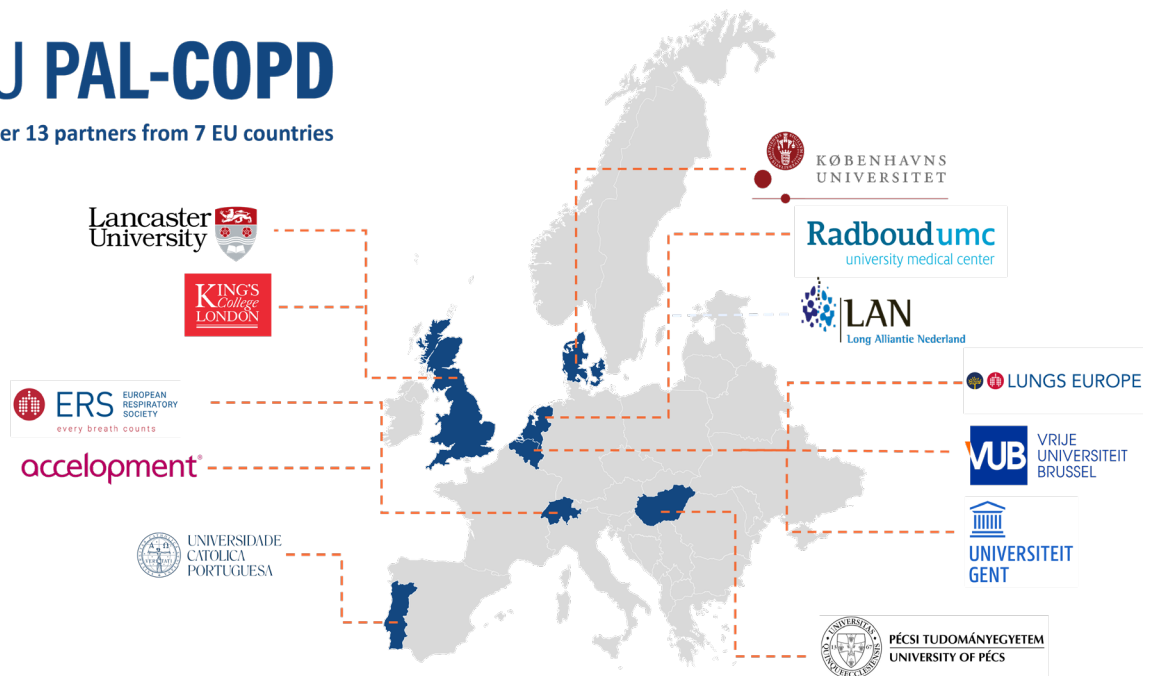
 [info@eupal-copd.eu](mailto:info@eupal-copd.eu)

  [@eupalcopd](https://www.youtube.com/@eupalcopd)




## EU PAL-COPD

brings together 13 partners from 7 EU countries



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