

# OECD for Patients WG

*Enhancing Patient Involvement in Cancer Care and Research*

## Key Updates and Plan of Action

 Roxana Plesoianu

 11 June 2025



# Objectives of the OEI for Patients WG 2025

Objective	Setting up the WG Steering Committee	Expanding Membership of the WG	Developing a Model for Patient Involvement in Cancer Care and Research	Participating in the A&D Expert Consensus Meeting on OEI Standards	Article on OEI Magazine	EC Actions: ALTHEA & CCI4EU
Status	Completed	Ongoing	Ongoing	Completed	Completed	Ongoing
Timeline	Q1 2025	Q1 2025 →	Q1 2025 – Q1 2026	Q1 2025	Q2 2025	2025



The WG Steering Committee was elected  
in January 2025

**Delia Nicoară**

Chair of the WG, IOCN Cluj-Napoca, Romania

**Paulina Bravo**

Director of Patient Education and Involvement,  
Fundación Arturo López Pérez, Santiago, Chile

**Alexandre Brutti**

Board Member, LuCE Lung Cancer Europe,  
Paris, France

**Francesco De Lorenzo**

President, Federazione Italiana delle Associazioni  
di Volontariato in Oncologia (FAVO), Italy

**Caitríona Higgins**

Cancer Patient Partnership Lead,  
Beaumont RCSI Cancer Centre, Dublin, Ireland

Our Members



**Silva  
Mitro**

Veneto Institute  
of Oncology  
Padova, Italy



**Daniela  
Costardi**

Veneto Institute  
of Oncology  
Padova, Italy



**Karin  
Svedberg**

Skånes University  
Hospital  
Lund, Sweden



**César Muñoz  
Sánchez-Miguel**

Centro Oncológico  
Clara Campal  
Madrid, Spain



**Kathi  
Apostolidis**

FAVO  
Rome, Italy



**Emmanuelle  
Hoche**

UNICANCER  
Rouen, France



**Kristina  
Isacson**

Sahlgrenska CCC  
Göteborg, Sweden



**Carina  
Dantas**

SHINE 2Europe  
Coimbra, Portugal

Eligibility Criteria to the WG



**Representatives  
OECl Member  
Centers**



**Cancer  
Patients  
Organisations**



**Individual  
Patients**



**Experts  
in Patient  
Engagement**





## Step 1: Mapping potential partner patient organisations

- One relevant organisation identified in each MS

## Step 2: Webinar to promote the WG in February 2025

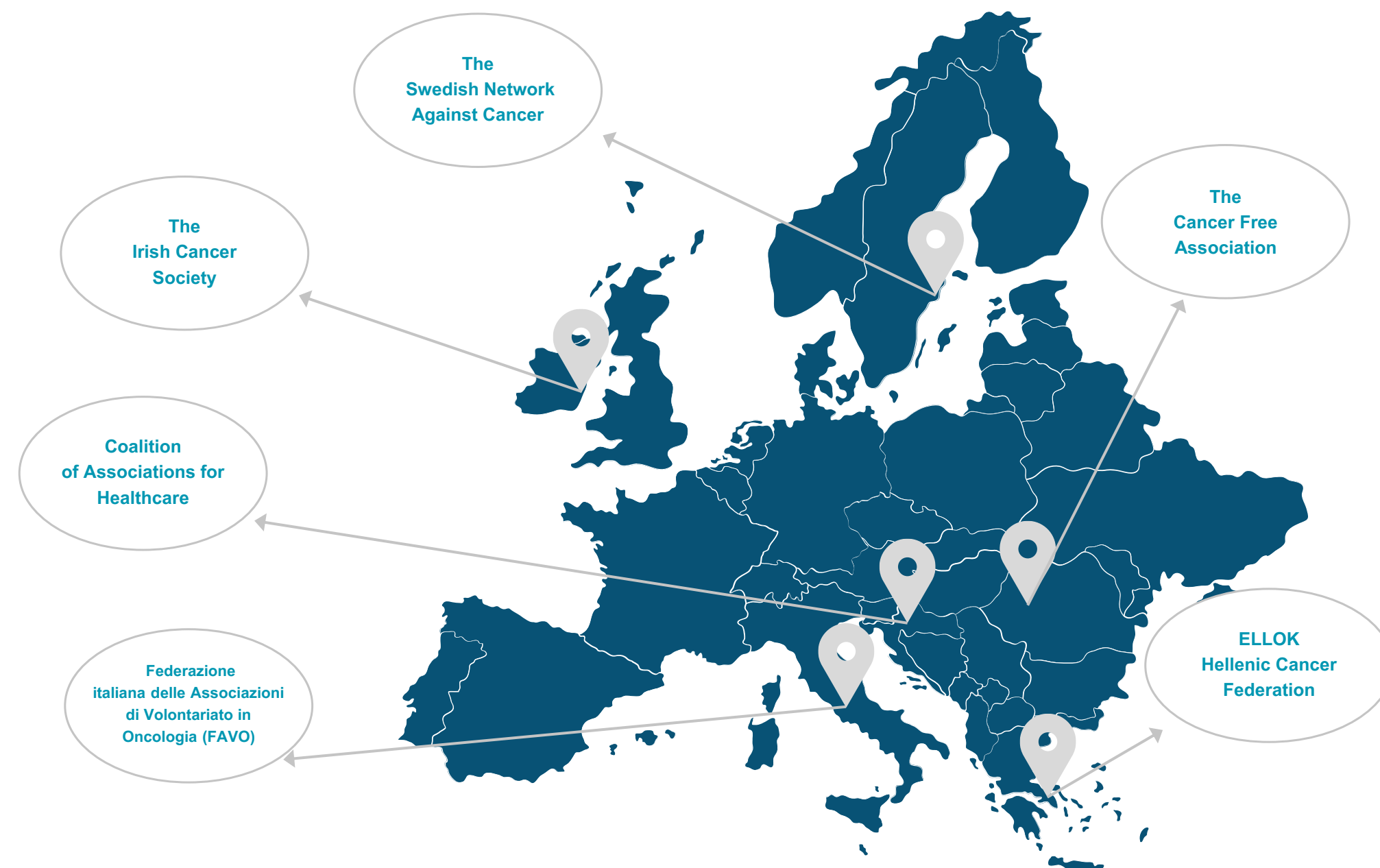
- Invited: 27 organisations
- Participants: 11 organisations

## Step 3: Individual meetings with patient organisations

# 6

## Patient Organisations

applied to the OECI Membership  
(Associate Member - Type C)



## Developing a Patient Involvement Model in Cancer Care and Research

### Step 1: Literature Review

An overview of existing patient involvement models to establish a baseline and help identify gaps

- Status: Completed

### Step 2: Patient Preferences and Needs Assessment

Direct Interviews with Patients > develop a survey and disseminate in OECl Member centres

- Status: Ongoing > Q2 – Q3 2025

### Step 3: Gap Analysis

Evaluate the gaps between current practices and patient needs/preferences to identify areas the model should address.

- Status: Ongoing > Q3 – Q4 2025

## Step 4. Drafting the Patient Involvement Model

- **Model Drafting**
  - Draft V.1 of the Patient Involvement Model
- **Refinement and Approval**
  - Review and approval by the WG, and OEI Board





# Step 5

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**WG Publication**

**Publishing the  
Patient Involvement Model  
in an influential journal**



## Involvement in EC Actions

- **ALTHEA**
  - A European initiative aimed at providing remote, psychological support through digital platforms
- **Comprehensive Cancer Infrastructures for Europe (CCI4EU CSA)**
  - Following ECPC's withdrawal, CCI4EU ensured continuity of patient involvement in the action by involving the OEI for Patients Working Group
  - Amendment approved (Nov 2024): WG embedded at multiple CSA levels





# Patient Voices Integrated in CCI4EU through our WG



## Deep Dive Participation

A patient representative is actively involved as an expert in the Deep Dive intervention in Ireland

As part of WP6 – Deep Dives



## Involvement in CB Conferences

Patient representatives involved in 2<sup>nd</sup> CB Conference + co-chair of the 3<sup>rd</sup> CB Conferences

WP5 – CB Conference



## Online Courses

OECl for Patients WG involved in design and delivery of the 5<sup>th</sup> CCI4EU Online Course

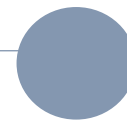
WP5 – Online Courses



# CCI4EU Activities where we will further involve our WG



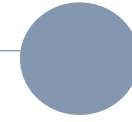
## WP 6: Patient Pathways



OECI for Patients WG will evaluate the PPs produced through DDs targeting pathway design



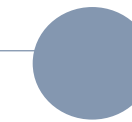
## Dissemination WP8: Task 8.1



WG Members will promote the CSA through their communication channels



## Review key deliverables



OECI for Patients WG will evaluate key deliverables produced within the CSA





# WG Article on the OECl Magazine N.1 2025

*Putting Patients at  
the core of Cancer  
Care and Research*

**OECl Working Groups**

## The OECl for Patients WG: Putting Patients at the core of Cancer Care and Research

**Delia Nicoară<sup>1</sup>, Kathi Apostolidis<sup>2</sup>, Paulina Bravo<sup>2</sup>, Alexandre Brutti<sup>2</sup>, Daniela Costardi<sup>2</sup>, Carina Dantas<sup>2</sup>, Francesco De Lorenzo<sup>2</sup>, Caitriona Higgins<sup>2</sup>, Emmanuelle Hoche<sup>2</sup>, Kristina Isacson<sup>2</sup>, Silva Mitro<sup>2</sup>, César Gregorio Muñoz Sánchez-Miguel<sup>2</sup>, Roxana Plesoianu<sup>3</sup>**

1. Chair of the OECl for Patients Working Group  
2. Member of the OECl for Patients Working Group  
3. The Organisation of European Cancer Institutes, Operations Manager

The OECl for Patients Working Group, under a revitalised identity marks a major step forward in cancer care and research across the Organisation of European Cancer Institutes (OECl). The group, drawing on the expertise of international leaders in patient involvement, patient partnerships and cancer care coordination, represents a collaborative effort between OECl Member centres, patients, and healthcare professionals.

At the OECl Oncology Days 2024, a landmark gathering of the world's leading oncology experts, the OECl for Patients WG presented its vision and mission, marking a pivotal moment in the organisation's commitment to patient-centred care.

The OECl for Patients WG, representing a natural evolution of patient-centred care in institutional quality frameworks, promotes personalised, multidisciplinary, high-quality cancer care and research in a seamless process. Now in their most mature phase, the A&D Standards feature a dedicated chapter on Patient Involvement, which, as a core principle of the OECl for Patients WG, represents a natural evolution of patient-centred care in institutional quality frameworks.

**Activities**

The OECl for Patients WG exercises to analyse existing patient involvement models, both at the institutional and individual levels, to ensure that patient voices are heard and acted upon.

**The WG Steering Committee**

**Delia Nicoară**  
Chair of the WG, IOCN Cluj-Napoca, Romania

**Paulina Bravo**  
Director of Patient Education and Involvement, Fundación Arturo López Pérez, Santiago, Chile

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Board Member, LuCE Lung Cancer Europe, Paris, France

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**Caitriona Higgins**  
Cancer Patient Partnership Lead, Beaumont RCSI Cancer Centre, Dublin, Ireland

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on patient involvement and empowerment that will appear in the upcoming A&D User Manual V.4, to be published on 1 July 2025. In addition, WG Member Paulina Bravo is now an Elected Member of the A&D Board.

Beyond internal OECl initiatives, the group is also making its mark in Europe's cancer research landscape. Through the CCIEU Coordination and Support Action, WG Member Alexandre Brutti provided expert input in the deep-dive intervention to enhance Ireland's comprehensive cancer infrastructure.

Alongside Chair Delia Nicoară, he co-organised the fifth CCIEU online course - an insightful webinar on patient empowerment and patient-centred care.

Involvement in ALTHEA, another prominent European initiative aimed at providing high-quality, remote, psychological support through digital platforms, further emphasizes the working group's strategic importance within OECl's broader agenda.

Key milestones on the horizon include the finalisation of the comprehensive patient involvement model, its widespread implementation across OECl centres, and continued contribution to European cancer initiatives. Together, these efforts are reshaping the future of oncology, ensuring that cancer care becomes more inclusive, responsive, and truly attuned to the voices and needs of patients.

**The role of support groups in patient empowerment**

In the changing medical landscape, the role of patients has evolved dramatically. They are no longer passive recipients of care; they have become active participants, collaborators and advocates for their own causes and for the communities they represent. Patient engagement is not just a trendy concept; it is actually a fundamental change that can improve health outcomes, ensure quality of healthcare and facilitate communication. Work in this area focuses on connecting the individual actions of patients with the collective efforts of cancer patient associations, creating a living ecosystem where every voice matters.

The mission behind this approach is clear and firm: **to empower patients by integrating them into the decision-making processes of the healthcare system.** This means informing them about their treatment plans and medical rights, encouraging their active participation in the decisions that affect their lives, and promoting more effective communication with healthcare professionals. The result is not only greater adherence to treatment, but also the creation of an environment where shared decision-making becomes common practice. Efforts do not stop at the individual level. The aim is to tackle the power of communities and patient associations to advocate for systemic change so that health systems become transparent, responsive and equitable. By institutionally including patients' perspectives at all levels, from day-to-day interactions in hospitals to institutional strategies, a model of care that truly responds to people's needs can be built.

The long-term vision looks to a future where patients are not just participants, but active partners in the design and improvement of healthcare. It is a world in which their involvement goes beyond self-advocacy and becomes a broad collaborative effort in which healthcare providers, patients and patient advocates work together to innovate and improve care. In this vision, cancer patient associations play a key role in amplifying patient voices, advocating for policies that eliminate inequities and using technology to make health more accessible. Hospitals become centres of partnership, where transparency and a patient-centred approach are everyday realities. Achieving this vision requires commitment, creativity, and, above all, a willingness to listen, which are principles that underpin all initiatives in this field.

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# THANK YOU

for your attention

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📍 *Organisation of European Cancer Institutes*