

OEI for Patients WG

Enhancing Patient Involvement in Cancer Care and Research

Strengthening Patient Involvement in Comprehensive Cancer Care



Dr. Delia Nicoară



11 June 2025

Organisation of European Cancer Institutes - OEI



Objectives of the session

- Highlight the value of meaningful patient involvement →
- Present best practices and real-world insights →
- Explore challenges and outline practical solutions →
- Promote collaboration among stakeholders



Why Patient Involvement Matters

Patient voice = the foundation stone of person-centered care

Situation in Europe (2022-2023)

Patients with multiple chronic diseases	→	1 in 3 Europeans aged >65 (OECD, 2023)
Costs of chronic diseases in the EU	→	€700 billion annually (European Commission, 2023)
Average degree of involvement reported	→	< 50% of patients feel involved (Health at a Glance: Europe 2022)

Example: WHO Europe 2020-2030 strategy includes 'patient engagement' as a pillar of health system reform.



The real impact of patient involvement

✓ Better clinical outcomes

Patient participation **increases** therapeutic adherence by up to **20-30%** (WHO, 2022). Study in oncology (Brown et al., 2020):

Patients involved in decision-making → **+15% 2-year survival** vs. passive.

✓ Increased relevance of research

Over 85% of clinical research is considered irrelevant by patients (Chalmers et al., 2014).

Studies with patient involvement have **20-25% higher** recruitment rates (NIHR UK, 2019).

✓ Democratic legitimacy of policies

EU projects (e.g. Horizon 2020, IMI2) call for mandatory inclusion of patients in decision-making boards.



Levels of patient involvement in oncology

Participation spectrum (Adapted from IAP2 Framework)

Level		Definition
Inform	→	The patient is informed, without having decision-making influence
Consult	→	The patient's opinion is sought but decisions are made by specialists
Involve	→	The patient's opinion is sought but decisions are made by specialists
Collaborate	→	Equal partnership between patient and professionals in decision making



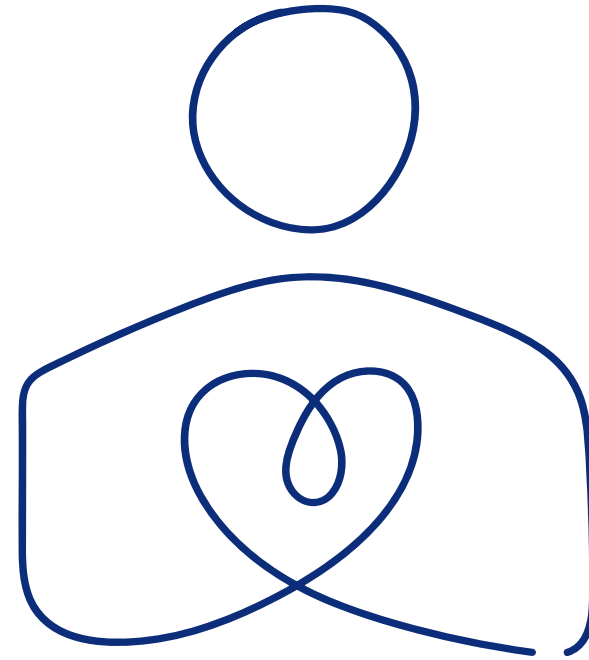
Levels of patient involvement in oncology

Examples by cancer are continuum stage

Stage	Practical example	Level
Prevention	Co-designed HPV vaccination awareness campaigns with patient advocates	Collaborate
Diagnosis	Patient feedback used to develop diagnostic information materials	Consult / Involve
Treatment	Joint decision-making on treatment options with oncology team	Involve
Survivorship	Peer-led support groups for cancer survivors	Empower
End-of-life care	Co-creation of palliative care plans between patients and care teams	Collaborate



OEI & Patient Involvement in Comprehensive Cancer Care



OEI mission: To promote a patient-centred, comprehensive, and quality-assured approach to cancer care across Europe.

Models of involvement:

- ✓ Patient advisory boards involved in hospital governance.
- ✓ Experience-Based Co-Design (EBCD) of services.
- ✓ Multidisciplinary care teams that include patient advocates.
- ✓ Direct involvement in accreditation reviews and strategic planning.



Patient Journey Prevention to Diagnosis

Journey stage

Education
(Primordial
Prevention)

Information
(Primary
Prevention)

Diagnosis

NGO role

Health education in schools and communities
Campaigns on lifestyle risks
Materials adapted to literacy and culture

Promoting screening services
Patient navigators for underserved groups
Online info sessions and tools

Emotional and legal support
Community volunteers aiding access
Patient guides: "what to expect"

Hospital role

Medical endorsement of materials
Participation in outreach
Training community leaders/teachers

Provide access to free screening
Integrate NGOs in referral systems
Feedback on participation data

Fast access diagnostic pathways
Joint communication protocols
NGO inclusion in outpatient services



Patient Journey Treatment & Survivorship

Journey Stage

NGO Role

Hospital Role

Treatment

Psychosocial **support** groups
Transport & logistics assistance
Distributing comfort/support kits

Multidisciplinary integration
Transparent care pathways
Quality assurance through feedback loops

Survivorship

Nutrition and lifestyle programs
Sports and **mental health** activities
Peer mentoring and social reintegration

Personalized **follow-up plans**
Referrals to NGOs/community services
Co-host survivorship events and education



Real-World Case Study: Patient Co-Design in Survivorship Care

Gustave Roussy (France)

Context:

Former cancer patients collaborated with care teams to redesign post-treatment survivorship services.

Patient involvement included:

- Identifying key unmet needs (fatigue, return to work, emotional recovery)
- Co-developing education materials and digital tools
- Participating in service evaluation and follow-up redesign

Impact:

- ✓ Improved patient satisfaction
- ✓ Better follow-up adherence
- ✓ Scaled to other French centers via the Unicancer network

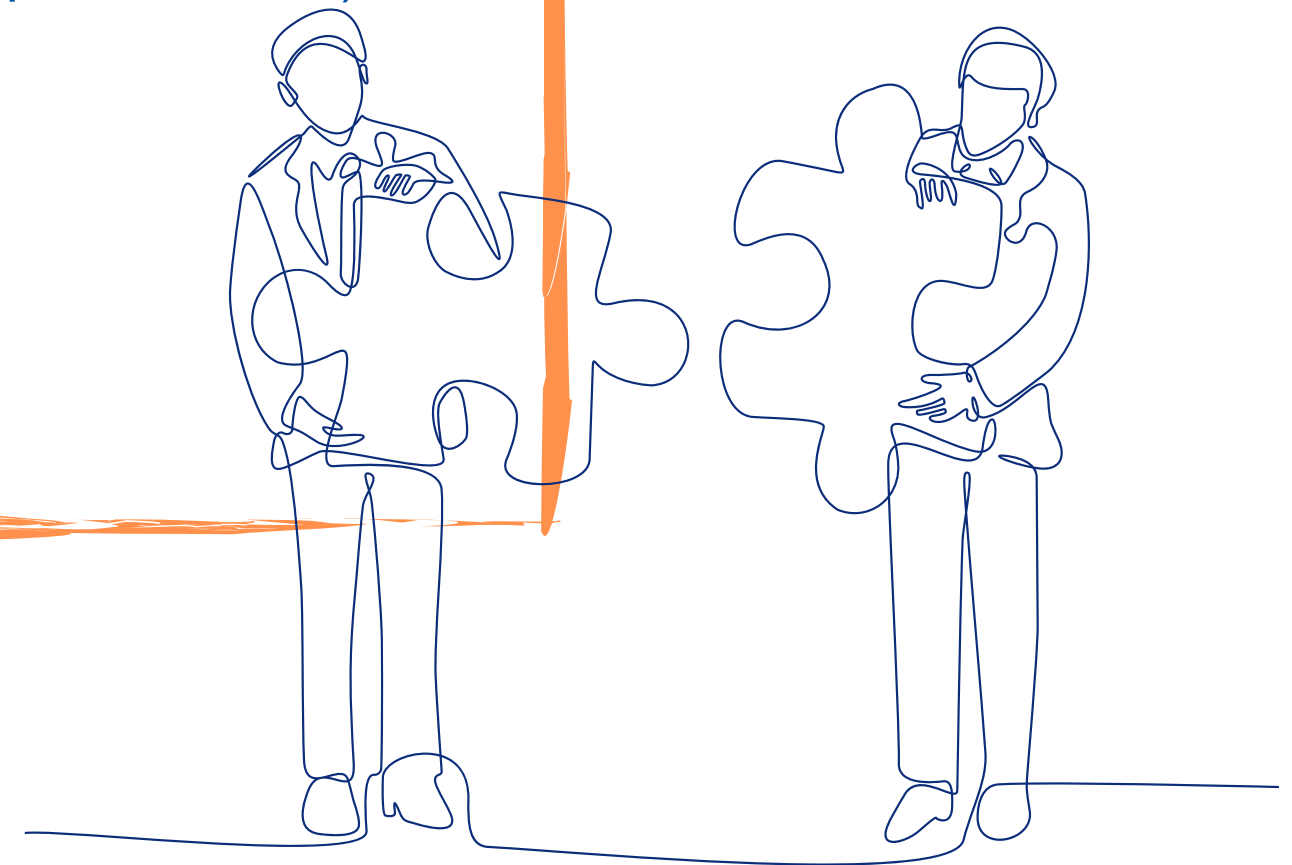


“Being part of the design team helped me feel heard — and it changed how care teams see survivors like me: as partners, not just patients.”

— Breast cancer survivor & advocate at Gustave Roussy

Challenges and Barriers

- Institutional resistance or inertia
- Tokenism vs. genuine involvement
- Capacity, literacy, training (both for patients and professionals)
- Equity and diversity in patient representation
- Fragmentation of care and services
- Power dynamics and hierarchical culture
- Time and resource constraints
- Lack of supportive policy and infrastructure



Models of involvement

Individual Patient Engagement

Direct involvement of the patient in their own care, research, and service improvement, as an expert by experience.



Forms of engagement

Patient as a member of the multidisciplinary team

Participation in therapeutic decisions (shared decision-making)

Structured feedback (e.g., surveys, post-treatment interviews)



Examples

Patient-consultant co-creating a post-chemotherapy guide

Patients involved in testing home-monitoring apps

Training for healthcare professionals co-delivered with cancer survivors



Models of involvement

Local NGO-Driven Engagement

Community-based NGOs facilitating the patient–hospital relationship and offering personalized support.



Forms of engagement

Patient navigators in hospitals (information + emotional support)

Local awareness and screening campaigns

Psychological and educational support groups

Examples

“Amazonia” Association (Romania) – support for women with breast cancer in hospitals in Cluj and Bucharest

Local NGO offering nutritional counseling in partnership with oncology clinics

Volunteer-driven transport programs for patients in rural areas



Models of involvement

Regional NGO-Led Engagement

NGOs operating at a regional level, supporting service integration, advocacy, training, and participatory research.



Forms of engagement

Training programs for patient ambassadors across counties

Joint programs with regional hospitals: psycho-oncology, social reintegration

Co-creation of regional quality care policies



Examples

Regional federations of patient associations (Transylvania, Moldova) participating in regional health boards

Training for medical staff in empathetic communication co-designed with patient trainers

Partnerships in regional research consortia studying quality of life



Models of involvement

National NGO & Advocacy Networks

National networks or federations of NGOs influencing public policy and promoting systemic patient involvement.



Forms of engagement

Participation in Ministry of Health working groups

Contribution to national quality standards (e.g., best practice guidelines)

National digital platforms for collecting patient experience data



Examples

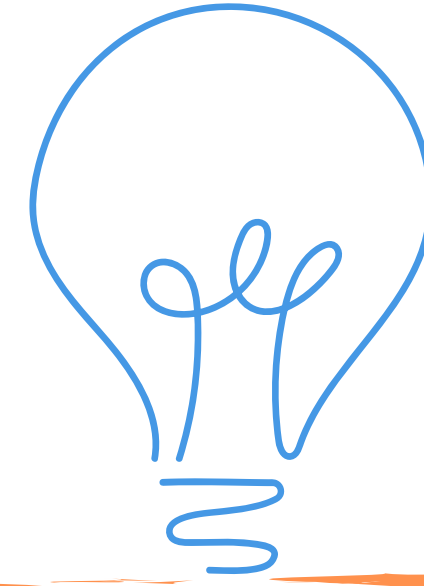
National Coalition of Patient Organizations with Chronic Conditions (CNOPAC)

EUPATI Romania member associations training "patient experts" for clinical research

Involvement in the National Cancer Plan through public consultations



Enablers and Solutions



- Governance & leadership support
- Clear frameworks (e.g., EUPATI, EORTC PPI models)
- Capacity building: training, mentoring, resources
- Feedback loops and evaluation of impact
- Co-design and co-production
- Diverse and inclusive engagement strategies
- Digital tools and platforms for engagement



Interactive Moment



SCAN ME



Future Directions

Vision for the next 5 years in OEI and beyond

Integration of patient involvement in:

- Comprehensive Cancer Centres
- EU Cancer Mission / Beating Cancer Plan
- AI & digital tools, survivorship, rare cancers



Call to Action

- ✓ Involve patients early and often
- ✓ Co-create, not just consult
- ✓ Join OEI4patients



OECI4Patients Group



Yvette



Claudio



Karin



Carina



Francesco



Daniela



Elena



Roxana



Marie



Emmanuelle



Kathi



Caitriona



Silva



Nina



Alex



Ana



Tania



Delia



Giovanni



Alexandre



Paulina



Kristina





THANK YOU

for your attention

Dr. Delia Nicoară

 [Linkedin: Delia Nicoara](#)

 Chairperson OEI4patients