

Patient organizations involvement in Comprehensive Cancer Centres-CCCs & Cancer Centers-CCs

Feedback on the Document on the OEI Patients Working Group

Francesco de Lorenzo

Kathi Apostolidis

OEI Oncology Days 2024 – Helsinki

Organisation of European Cancer Institutes - EEIG





350 FEDERATED ASSOCIATIONS

REGIONAL COMMITTEES

- FAVO Lombardia
- FAVO Lazio
- FAVO Puglia
- FAVO Piemonte-Liguria-Val d'Aosta
- FAVO Toscana
- FAVO Campania
- FAVO Sicilia
- FAVO Triveneto
- FAVO Calabria
- FAVO Umbria-Marche-Abruzzo

50 Information desks in all CCCs

25.000 VOLUNTEERS

Alliance between
patient organizations, scientific
societies, institutions



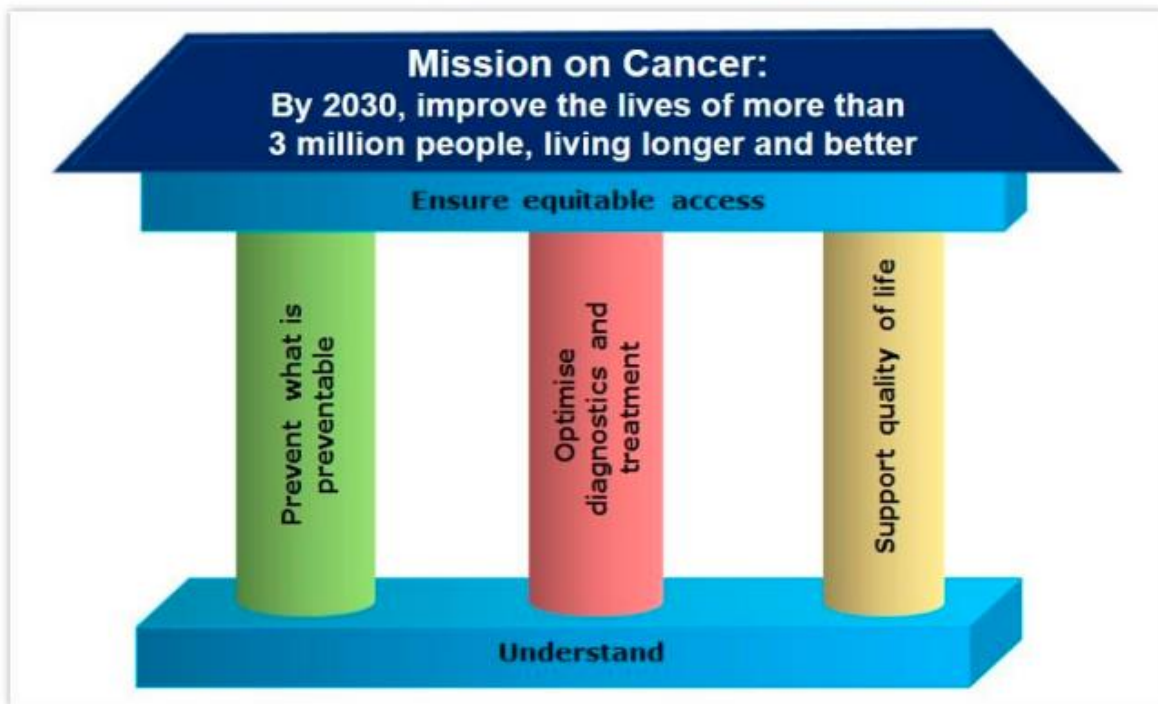
New needs, new rights: **THE CHALLENGES OF CANCER PATIENT ASSOCIATIONS**

Information and Communication	Disparities	Rehabilitation (phisc, nutritional, sexual, cognitive and social)	Mother and father after cancer
Patients and caregivers rights	Right to be forgotten	Pain therapy and palliative care	Rare cancers
Neglected tumors	Follow up and QoL for survivors	Life after cancer	Research





Mission on Cancer



“By 2030, improve the lives of more than 3 million people, living longer and better”

Specific objectives:

1. understanding
2. prevention
3. diagnosis and treatment
4. quality-of-life

Operational objectives (transversal):

1. Ensure equity and access to knowledge, research and care
2. Promote innovation, test, validate, demonstrate and upscale solutions
3. Address childhood cancer and personalised medicine
4. Engage with the cancer community, citizens/patients and society at large



where CCCs/CCs can collaborate with cancer patient organisations



Actions: diagnostics and treatment

- Support the creation of a Network of Comprehensive Cancer Infrastructures, integrating research aspects
- Develop twinning programmes for capacity-building
- Develop a clinical trial programme on diagnostics
- Develop a clinical trial programme on treatments

Actions: quality of life

- Collect and analyse data on today's unmet needs of cancer patients and survivors
- Develop early predictors for quality of life
- Design monitoring programmes for survivors of childhood cancer
- Set up of a European Cancer Patient Digital Centre



EU Missions – synergies with EU policies and initiatives

Initiatives that can help achieve the goal of the EU Mission on Cancer

- Horizon Europe partnerships
- European Cancer Information System
- Chemicals Strategy for Sustainability
- Zero Pollution Action Plan
- HealthyLifestyles4all initiative
- Strategic Agenda for Medical Ionising Radiation Applications
- Research and Training Programme (Euratom)
- Pharmaceutical Strategy

Initiatives that can act as 'enabler' for the EU Mission on Cancer:

- European Health Data Space
- Knowledge Centre on Cancer (KCC)
- EIT & KICs
- European Universities Initiative

Initiatives that the EU Mission of Cancer are expected to serve:

- Artificial Intelligence Agenda
- European Data Strategy
- Digital transformation and skills
- New European Bauhaus initiative

National activities



The report's main recommendations include among other:

- **stronger EU action to address the key risk factors of cancer**
- **extension of screening schemes and launch of a EU platform for national screening centres**
- **facilitating cancer patients' access to cross-border health care and clinical trials, developing European multi-centre clinical trials**
- **Calling for transparency throughout the pharmaceutical and equal access to innovative cancer treatments**
- **holistic approach and multidisciplinary cancer research for improvement of cancer prevention, diagnosis and treatment**
- **additional funding for the ERNs and integration into the national health systems**
- **establishment of the Knowledge Centre on Cancer**



Why is it important that CCCs/CCs collaborate with patient organizations?

- The Comprehensive Cancer Centre (CCC) is the optimal, inclusive of many stakeholders, structure for driving innovation & delivery of high-quality multidisciplinary care, integrated with both research and education.
- **By 2030 90% of eligible cancer patients is expected to be treated in CCCs.**
- Prominent and active role of patient organisations & patients in their treatment and care, is key element of the EU Cancer Plan & Cancer Mission & of the OEI A&D.
- Patients involvement is present in the Clinical Trials Directive, Commission policy recommendations on Cancer Care, Research, Quality of Life of patients and families, rehabilitation and survivorship care.
- Patient Organizations involvement is instrumental for implementation of the above recommendations.



OEI CCCs/CCs & the EPIC-CARE WG will contribute to Cancer Mission recommendations

- **Understanding Cancer:**

Recommendation 1: Launch UNCAN.eu – a European Initiative to Understand Cancer

- **Personalised Medicine:**

Recommendation 5: Advance and implement personalised medicine approaches for all cancer patients in Europe

- **Improve QoL of cancer patients and survivors, family members and carers:**

Recommendation 7: Develop an EU-wide research programme and policy support to improve the quality of life of cancer patients and survivors, family members and carers, and all persons with an increased risk of cancer,

- **European Network of CCCs:**

Recommendation 10: Set up a network of Comprehensive Cancer Infrastructures within and across all EU Member States to increase quality of research and care and indeed

- **Transform Cancer Culture:**

Recommendation 13: Transform cancer culture, communication and capacity building.



Accreditation and Designation Programme

Appendix II

OECI Qualitative Standards

1. Governance of the cancer centre/institute	5
2. Organisation of quality systems	7
3. Patient involvement and empowerment	10
4. Multidisciplinarity	13
5. Prevention and early detection	15
6. Diagnosis	16
7. Treatment	18
8. Research	24
9. Education and training	28

It is the mission of the cancer center
to encourage patient involvement
in services



Chapter 3: Patient involvement and empowerment (standards 19 to 28)

Patient involvement	
Standard 19	
It is the mission of the cancer centre/institute to encourage patient involvement in services.	
1.	CORE The cancer centre/institute involves patients and patients' voluntary organisations and support groups in the planning and organisation of services.
2.	The standard process of introducing new practices in clinical care ensures that patients are involved.
3.	There is a committee representing patients and serving as a link between the cancer centre/institute and the patients for advice and consultation.

Patient education programmes	
Standard 20	
Patient education programmes are in place.	
1.	There are policies in place for patient education programmes where responsibilities and accountabilities of the staff are stated.
2.	CORE There are patient education programmes that aim at improving patient understanding of their illness, diagnosis, including information on self-care and how to manage multiple aspects of their illness or survivorship.
3.	The cancer centre/institute makes specific provisions for access for individuals with disabilities and special needs (e.g. reduced mobility, visual and hearing difficulties).
4.	CORE An information and support centre is available in the cancer centre/institute and easily accessible for staff, patients, family members and caregivers.
5.	The cancer centre/institute organises public events to showcase advances in cancer research.

Patients' rights and preferences	
Standard 21	
The cancer centre/institute has a policy on patients' preferences.	
1.	The cancer centre/institute has a policy on respecting patients' preferences (religious, cultural, social).

Patient information	
Standard 22	
Information is provided to patients.	
1.	CORE The cancer centre/institute provides information material that is readable, up-to-date, appropriate and available in languages commonly spoken by the population served.
2.	Information about diagnostic and treatment options is provided.
3.	The information includes information about follow-up after treatment.

Informing patients about their care	
Standard 23	
There are procedures for informing patients about the diagnostic results, treatment and follow-up, and survivorship support.	
1.	CORE There are procedures in place which specify how and by whom patients are informed about their diagnostic results, treatment options, follow-up, and survivorship support, which involve shared decision-making.
2.	Expertise and specific training on communicating with patients and their families is available for staff.
3.	The information communicated to the patient is recorded in the patient's record.
4.	If patients are referred to another healthcare provider, they are informed about the continuity of their care.
5.	Patients receive information about their contact person for all matters related to their care.
6.	CORE All patients are given contact information of clinical staff in case of emergency.

Informing patients on admission	
Standard 24	
Cancer patients are informed about the cancer centre/institute admission and welcoming procedures.	
1.	All patients visiting the cancer centre/institute receive general information about the hospital.
2.	Detailed information about the admission procedure is available and communicated to patients.
3.	Information about patients' associations and about self-help and support groups is given to patients and their caregivers.

Discharge procedure, follow-up and survivorship care planning	
Standard 25	
Discharge procedure and related care plans are defined.	
1.	CORE There is a defined discharge procedure including giving information on further treatment, follow-up, re-admission and home care.
2.	The cancer centre/institute has processes to inform the patients' General Practitioner of a transfer of care.
3.	The patient is provided with an individual survivorship plan which is discussed with the patient and includes details of all support services and support groups available .
4.	The patient is provided with an individual plan for end-of-life care, which is discussed with the patient and caregivers.

Chapter 3: Patient involvement and empowerment (standards 19 to 28)

Patient involvement	
Standard 19	
It is the mission of the cancer centre/institute to encourage patient involvement in services.	
1.	<p>CORE The cancer centre/institute involves patients and patients' voluntary organisations and support groups in the planning and organisation of services.</p>
2.	The standard process of introducing new practices in clinical care ensures that patients are involved.
3.	There is a committee representing patients and serving as a link between the cancer centre/institute and the patients for advice and consultation.



Collaboration Areas in Cancer Policy & Research of Patient Organizations (POs) with CCCs/CCs

POs representation
in CCCs/CCs
governing bodies
and committees

Cancer Prevention
– Early detection

Screening &
diagnosis

Cancer Pathways

Addressing
inequities in cancer
detection and care

Clinical Trials

Cancer Research

Education &
Support

Survivorship Care

Transform Cancer
culture



Cancer Policy & Research areas in which CCCs/CCs are called to collaborate

Policy area recommendations	Patient organisations (POs) contribution
POs representation in CCCs CCs governing bodies & committees	<p>CCCs/CCs can formally include POs representatives on advisory boards, steering committees, and governance bodies.</p> <p>POs involvement ensures that patient perspectives are considered during strategic planning, resource allocation, and decision-making processes.</p>
Cancer Prevention – Early detection	<p>POs organize awareness campaigns on tobacco & alcohol cessation, healthy diet, & physical activity. Collaboration/Co-creation with CCCs/CCs for educational materials and workshops for patients and the public.</p> <p>POs advocate for cancer prevention, early detection, and access to quality care. They raise awareness about cancer-related issues, ensuring that CCCs/CCs prioritize patient needs.</p>



Policy area recommendations	Patient organisations (POs) contribution
Screening & diagnosis	POs collaboration with CCCs/CCs for awareness raising about importance of regular screenings. Together they can co-design organisation of community events, reaching out to vulnerable population groups, distribution of educational materials, and encouragement for participation in screening campaigns
Addressing inequities in cancer detection & care	POs advocate for affordable & accessible cancer detection, treatments & care. In collaboration with CCCs/CCs POs can identify national/regional barriers & propose solutions.
Cancer Pathways	POs can collaborate with CCCs/CCs to develop patient-centered care pathways, i.e. jointly deciding on treatment options, implementing shared-decision-making in cancer care, considering patient preferences, needs, ensuring timely access to and continuity of care.



Policy area recommendations	Patient organisations (POs) contribution
Clinical Trials	<p>In the context of the Clinical Trials Directive patients can contribute by providing input, assume advisory roles, ensure safety, privacy and ethics, enhancing transparency.</p> <p>Collaboration with POs on clinical trials and studies, (in roles other than subjects thereof), ensures that patient perspectives are considered, leading to more relevant & impactful trials & research outcomes.</p> <p>POs can offer insights for patient recruitment for clinical trials, educate patients about the importance of participation in clinical trials & research & dispel misconceptions.</p>
Cancer Research	<p>Several POs already participate actively in EU funded research projects, & they can contribute to research initiatives led by CCCs/CCs. POs advocate for transparent data sharing, allowing researchers to access real-world patient data for better insights.</p> <p>Their insights help shape research priorities, study designs, and are instrumental for advisory boards, focus groups, surveys, pilot projects.</p> <p>CCI4EU foresees educational module for patients empowerment for participation in cancer research projects providing ethical insights, contributing to privacy, informed consent, communication and dissemination project requirements</p>

**Policy area
recommendations**

Patient organisations (POs) contribution

**Education and
support**

POs provide education, emotional & social support to cancer patients & their families. CCCs/CCs can co-design & co-create with POs educational programs, information materials, online platforms, workshops, & counseling services.

Joint efforts with CCCs/CCs teams enhance patient empowerment, improve adherence to treatment plans, & foster a sense of community among cancer patients & staffers of CCCs/CCs.

Survivorship Care

POs provide emotional & social support, create support groups, organize survivorship workshops. With CCCs/CCs they can co-design survivorship programs that address survivors' physical, emotional, & social needs for social and work-life reintegration & may include support groups, counseling, and survivorship care plans

POs can create survivorship programs that complement CCCs/CCs services to monitor survivors' health, address late effects, & improve quality of life.

Policy area recommendations	Patient organisations (POs) contribution
<p>Quality of Care Improvement- Quality of Life</p>	<p>POs are a source of valuable feedback on CCCs/CCs services, facilities, & patient experiences (PROs/PREMs) that helps CCCs identify areas for improvement.</p> <p>Quality improvement initiatives, co-designed & implemented with POs ensure that CCCs/CCs continuously enhance their care delivery & patient satisfaction, reflecting attention to patient preferences and needs.</p> <p>POs can provide resources & emotional support to families affected by cancer, working alongside CCCs/CCs social workers & counselors, advocate for policies that enhance patients' quality of life, including access to palliative care, psychosocial support, and financial assistance.</p>
<p>Transform Cancer culture</p>	<p>This is a key recommendation of the Mission on Cancer. The collaboration among POs, CCCs/CCs and OECl aims to change the prevailing attitude of Europeans towards cancer.</p> <p>It is foreseen in the CCCl4EU project and was part of the MoU between OECl-ECPC. It includes among other training for cancer stakeholders and education programmes/campaigns to raise awareness among the general public, including children & adolescents, in line with up-to-date scientific knowledge on cancers, their symptoms, risk factors, preventability, treatment options and impact on patients, survivors, their families and carers, and citizens with an increased risk of cancer.</p>

Adoption of OECD Qualitative A&D Standards 19-28

Since the role of cancer patient organisations and patients is instrumental in both the EU Cancer Plan and the Cancer Mission, in the Joint Actions CraNE, JANE, in the EU funded Projects CCI4EU, EUonQoL, CSA 4.uncan.eu, can.HEAL, as mentioned above,
Standards 19-28 should be equally mandatory for A&D as other clinical ones. The compliance of cancer centers to these standards for A&D should be assessed by an auditing team in which patient representatives participate. The revision and update of the A&D programme should include patient representatives to provide the patient perspective and insights, as users of the services offered by cancer centres.

In-depth qualitative survey of existing or planned collaborations of CCCs/CCs with patient organisations

Based on the analysis of the results of the April 2024 survey, there is need to conduct in the 3rd Quarter 2024, a more in-depth survey aiming to analyse characteristics of the existing/planned collaboration of the OECD CCCs/CCs.



Thank you for your attention!

Francesco de Lorenzo – Member of the OEI EPIC-CARE Working Group
President Italian Federation of Volunteer Patient Organizations - FAVO
Board Member of European Academy of Cancer Science - EACS
Past President of the European Cancer Patient Coalition - ECPC
fdelorenzo@favo.it

Kathi Apostolidis – Member of the OEI EPIC-CARE Working Group
Co-Founder and Past President Hellenic Cancer Federation - ELLOK
Past President of the European Cancer Patient Coalition - ECPC
kathi.apostolidis@gmail.com

