



OEI Patients Working Group

EPIC-CARE WG

Enhancing Patient Involvement in Cancer Care and Research

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Executive Summary

The present document presents the work of the founding members of the OEI Patient Working Group that has gathered for the first time in July 2023 to discuss how the WG could be organized.

The Working Group has actively collaborated with the assistance of the OEI the previous period to prepare the present EPIC-CARE Working Group Profile and Action Plan.

The present document presents the Mission, the membership eligibility criteria for increasing the capacity of the WG and the proposed Action Plan that will be complemented with a time plan after its approval.

There are already across Europe examples of collaboration of patients, on an individual basis as the French “patients partenaires” or the Greek patient associations of “Friends of Hospital ...”, however the OEI initiated Patients Working Group aims at collaboration of OEI accredited Comprehensive Cancer Centers (CCCs) and Cancer Centers (CCs) with the registered patient organisations operating in their communities, as well as with patient advocates.

This collaboration is foreseen in the OEI strategy and follows the suggestions and policy recommendations of the EU Cancer Plan and of the Cancer Mission and of the EU Joint Actions and projects implementing the concept of the Comprehensive Cancer Centers, the Quality of Life for cancer patients and survivors and of the increased role that cancer patients and survivors are invited to assume in their care and well-being.

The proposed model of collaboration is that of the OEI Patients WG acting as a Steering Committee, offering guidance, information, facilitation to both CCCs, CCs and patient organizations for starting in their cities or countries national hubs of the OEI WG.

The Working Group will gladly listen to the suggestions and comments of the OEI Board and of OEI members on the present document and appreciate the collaboration in starting the activities of the EPIC_CARE Working in the second semester 2024.

Mission of the Working Group

The Working Group Mission is to promote meaningful collaboration between cancer patient organizations and Comprehensive Cancer Centers (CCCs) and Cancer Centers (CCs), to ensure patient perspectives on cancer care are integrated into CCC activities and to foster active patient involvement in cancer research.

The above definition of the OEI Patients WG mission, that was drafted in consensus by the current members of the WG is also in line with the OEI strategy and values, EU Commission's Report "Governing Missions in the European Union"¹ stipulating the bottom-up approach to the EU missions, to solve problems important to European citizens, with the EU Cancer Plan that, even if it does explicitly mention the role of cancer patients' organizations in comprehensive cancer centers, on more than one occasions stresses the importance of comprehensive cancer care and of the quality of life for cancer patients and survivors.

Among the many initiatives and projects of the EU Cancer Plan aiming to offer state of the art cancer care and to support cancer patients and survivors, it is worth to mention the establishment of the EU Network of National Comprehensive Cancer Centres by 2025, the Quality and Life for Cancer Patient and Survivors, the CRANE²-Joint Action on the European Comprehensive Cancer Centers, the JANE³-Joint Action on EU Networks of Excellence, and indeed the CCI4EU⁴- Comprehensive Cancer Infrastructures for Europe project, led by OEI.

Similarly, the EPIC-CARE WG is in line with the Cancer Mission Board Recommendations:

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

¹ *Governing Missions in the European Union* - [ec_rtd_mazzucato-report-issue2_072019.pdf](https://ec.rtd.mazzucato-report-issue2_072019.pdf) (europa.eu)

² JA CRANE <https://crane4health.eu/>

³ JA JANE- <https://jane-project.eu/>

⁴ CCI4EU - <https://cci4eu.eu/>



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

The WG mission extends to a comprehensive approach that encompasses cancer prevention, cancer care delivery, cancer patient pathway, survivorship care, rehabilitation, research, rare cancers, and the empowerment of patients to actively participate in their care and in cancer research. Through these interconnected aspects, we are committed to ensuring that the patient voice resonates throughout all stages of cancer care and research, creating a unified and patient-centric landscape that maximizes the potential for improved patient outcomes and enhanced overall well-being.

The Working Group (WG) plays a pivotal role in ensuring seamless **collaboration among all EU-funded projects and Joint Actions**, coordinated by OECI including Joint Action on Networks of Excellence (JANE), CRANE, CCI4EU, can.HEAL⁵ and UNCAN.eu⁶, fostering a unified and synergistic approach towards advancing patient empowerment, cancer care, and Quality of Life.

In addition to the foregoing, the empowerment of patients is cultivated through comprehensive education and patient training initiatives, synergizing with the resources and expertise of the **European School of Oncology (ESO)** to equip patients with the knowledge and skills needed to actively engage in their cancer care journey.

Scope

Enhancing patient empowerment and involvement in cancer care and research.

The Working Group (WG) is established with the overarching scope of promoting patient empowerment and fostering active patient involvement with CCCs and CCs within the context of cancer care and research. The Working Group will operate collaboratively, recognizing the diverse and localized nature of cancer care and patient needs. The scope of the WG encompasses the following key areas:

⁵ Can.HEAL - <https://canheal.eu/>

⁶ Uncan.eu - <https://canheal.eu/>



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- The WG facilitates **meaningful collaboration** between OEI-accredited CCCs and cancer patient organizations, promoting mutual understanding and shared goals.
- Recognizing the importance of **localized approaches**, the WG encourages the establishment of local antennas among CCCs and/or CCs and cancer patient organizations to drive collaboration, tailoring initiatives to the specific needs and priorities of different regions.
- The WG aims to **empower cancer patients and their families** by providing access to accurate information, resources, and educational opportunities that enhance their understanding of cancer primary and tertiary prevention, cancer care, treatment options, and support services.
- The WG actively **promotes the involvement of cancer patients in research activities**, including clinical trials and research projects, ensuring that patient perspectives influence research design, implementation, and outcomes.
- The WG supports through the OEI the growth and development of cancer patient organizations by providing **training, resources, and guidance**.

The WG operates with the understanding that each country, CCC or CC and patient organization has unique priorities and needs. It focuses on fostering collaboration and synergy at the national or regional level through the establishment of local antennas, allowing for tailored initiatives that address the specific challenges and opportunities within different geographic areas.

On a broader scale, the WG scope meets the scope of The Oncology Institute, Cluj-Napoca (IOCN), an OEI accredited CC, which is to work collectively at the European and international levels to improve cancer care and support for cancer patients, their families, and communities. The common aim is to create a unified voice for cancer patients, advocate for patient-centric policies, promote research and innovation, strengthen cancer patient organizations' capacity to empower patients and families effectively and ultimately to develop a collaborative relationship among patient organizations, and CCCs and CCs.

Membership of the Working Group

Working Group (WG) Membership and Operations

It should be understood though that this WG cannot operate without local antennas: this means that each OEI accredited CCC will collaborate mainly with the patient organizations in its region and individual patients in treatment or having completed it. The reason is that each country, each CCC and patient organization have different priorities and needs. The collaboration and interaction cannot be controlled/organized remotely from patients or CCCs/CCs in other countries, who can only share best practices and Information.

Eligibility and Selection Criteria

The WG is composed of a diverse and dynamic group of stakeholders committed to advancing patient empowerment and involvement in cancer care and research. Eligible for WG membership are members of

- 1. Comprehensive Cancer Centers (CCCs):** Representatives from OEI-accredited CCCs/CCs who demonstrate a commitment to patient-centered care and research, and a willingness to collaborate with patient organizations within their respective regions.
- 2. Cancer Patient Organizations:** Representatives from patient organizations with a preference for former ECPC members, with a proven track record of advocating for cancer patients' rights, supporting patient education, and actively engaging in cancer-related initiatives.
- 3. Individual Patients:** Individuals who have undergone cancer treatment or have experience as caregivers, offering a unique perspective on patient needs and challenges.
- 4. Experts in Patient Engagement:** Professionals with expertise in patient engagement, health communication, research ethics, and patient-centered care.

Expectations and Responsibilities of WG Members

- 1. Active Participation:** WG members are expected to actively participate in meetings, workshops, and collaborative initiatives, both at the local and broader levels.
- 2. Contribution to Discussions:** WG members contribute their insights, experiences, and expertise to discussions about patient involvement strategies, research priorities, and patient-centric care.
- 3. Regional Collaboration:** CCC representatives collaborate mainly with patient organizations and individuals within their region, recognizing that priorities and needs differ across countries and CCCs.
- 4. Sharing Best Practices:** CCCs, and patient organizations share best practices, successful patient engagement models, and innovative strategies for enhancing patient involvement.
- 5. Feedback and Input:** WG members provide feedback on proposed research projects, patient education materials, and policy initiatives to ensure they align with patient needs and perspectives.
- 6. Advocacy:** Patient organizations engage in advocacy efforts to promote patient-centered policies and support initiatives that enhance patient empowerment.
- 7. Capacity Building/Training:** CCCs and experts provide training and resources to patient organizations to strengthen their capacity in areas such as research involvement, advocacy, and patient support.
- 8. Local Antennas:** Recognize the importance of local antennas in facilitating effective collaboration between CCCs, patient organizations, and individual patients within their respective regions.
- 9. Assuring Unity:** Planning, organizing and delivering activities of the working group in the OECI annual conference and eventually in other relevant conferences to exchange information, best practices, news, and most importantly connecting all people in the antennas among them and with OECI.

Note: The WG recognizes that patient involvement is context-specific and operates on a decentralized model, with local antennas driving collaboration tailored to the unique needs of each region. By embracing local antennas and fostering regional engagement, the WG maximizes its impact in enhancing patient empowerment and involvement in cancer care and research.



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Objective – Action Plan

Objective: *The Working Group aims to foster active patient involvement and empowerment within Comprehensive Cancer Centers (CCCs) and Cancer Centers (CCs) through collaboration with cancer patient organizations and localized initiatives.*

WG Action Plan:

1. Establish Local Antennas:

- Identify OEI-accredited CCCs/CCs willing to collaborate and to establish formal interactions with cancer patient advocates, their organization and individual patients
- Identify patient organizations in the regions of operation of OEI-accredited CCCs/CCs, interested to get involved and collaborate with the CCCs.
- Inform both interested CCCs/CCs and patient organizations, patients and other stakeholders of the mission of this WG and of its founding partners, the values governing the WG operation and request their adoption.

2. Identify Regional Priorities:

- Conduct a comprehensive needs assessment in each region to understand patient and families' needs, priorities, preferences for involvement in cancer care and research, the health system in which cancer care is delivered, structure and organization of cancer delivery within each CCC/CC, how each CCC/CC envisions patient involvement in cancer care delivery and cancer research.

3. Collaborative Workshops and Seminars:

- Organize localized workshops and seminars to promote dialogue and understanding between CCCs/CCs and cancer patient advocates and their organizations on patient-centric care, patient involvement in cancer research, and on social benefits.

4. Patient Advisory Panels:

- CCCs/CCs establish patient participation in existing or new CCC/CC committees and WGs, panels comprising patients, survivors, and caregivers to provide ongoing feedback and insights into cancer care and research initiatives.

5. Patient Education and Empowerment Programs:

- Develop patient-centered educational programs and resources that empower patients to inform and support newly diagnosed patients with information about their diagnosis, treatment options, and available support services.
- Train patients and caregivers to read scientific papers, writing, reading, evaluating grant proposals, particularly regarding the actual participation of patients in a research program.

7. Advocacy for Patient-Centric Policies:

- Collaborate with patient organizations to advocate for the development and implementation of cancer and health policies that prioritize patient needs, rights, and equitable access to cancer diagnosis, quality cancer care, palliative care, rehabilitation, survivorship care

8. Share Best Practices:

- Create an online platform for sharing best practices, successful patient engagement models, and innovative strategies among CCCs/CCs, patient organizations, and patients. Also, provide training and support to patient organizations.

9. Regional Collaboration and Networking:

- Facilitate regular networking events and forums at the regional level to promote collaboration, knowledge sharing, and peer support.
- Facilitate bi-annual networking events at European level, possibly within the annual OEI congress, to strengthen the relations of the local/regional antennas and CCCS and develop a sense of community.

10. Promote Patient-Centric Communication:

- Encourage transparent and patient-centered communication between CCCs/CCs, patient organizations, and patients to ensure a seamless exchange of information and ideas.

Timeline: An estimated initial three-year period will be needed to build trust among highly regulated structures of CCCs/CCs and patient organizations so that they can foster a frank collaboration

The proposed Action Plan will be implemented over a period of one year with regular yearly updates, while regular assessments are foreseen to ensure progress and alignment with regional needs.

Time counts differently in patient organizations, since their membership is people from all walks of life, linked by the common experience of cancer. Therefore, everything takes more time and requires more patience and ability to make difficult concepts easily understood and also translate the lived patient experience to policy recommendations.

By implementing this focused Action Plan, the Working Group aims to create local/regional patient-centered ecosystems with OEI Comprehensive Cancer Centers/Cancer Centers and a European such network, promoting patient empowerment, active involvement, and improved cancer care and research outcomes.

Working Group Values

1. **Empowerment:** empowering cancer patients to actively participate in their treatment decisions and overall well-being.
2. **Advocacy:** standing up for the rights and needs of cancer patients and advocating for positive change in cancer-related policies.
3. **Patient-Centric:** putting the needs and preferences of cancer patients at the forefront of all initiatives and decision-making processes.
4. **Compassion:** demonstrating empathy and understanding towards cancer patients and their families during their journey.
5. **Inclusivity:** ensuring that all cancer patients, regardless of their background or circumstances, have access to support and quality care
6. **Collaboration:** encouraging teamwork and partner to maximize the impact and effectiveness of their efforts
7. **Transparency:** operating with openness and honesty in all organizational activities and interactions.
8. **Excellence:** striving for excellence in cancer care, research, and patient support services.
9. **Integrity:** upholding the highest ethical standards in their operations and relationships.
10. **Innovation:** embracing and promoting innovative approaches and technologies in cancer care and research.

1. **Education and Awareness:** conduct awareness campaigns and educational initiatives for patients and the public by each CCC and collaborating patient organisations.
2. **Patient Empowerment:** developing programs and resources to empower patients and patient orgs aiming to take an active role in their care and to set research priorities important to them.
3. **Capacity Building for Patient Organizations:** providing training to strengthen cancer patient organizations' capacity.
4. **Collaboration and Networking:** establishing collaborations with cancer centers, patient organizations, and stakeholders across regions, countries, Europe.
5. **International Engagement:** engaging with international organizations to promote global efforts in cancer prevention, care, quality of life and patient support.
6. **Communication and Information Sharing:** creating platforms for sharing knowledge, best practices, and updates across the network.
7. **Policy and Advocacy:** advocacy efforts to influence cancer-related policies and ensure patientcentric care on national and/or European level.
8. **Research and Innovation:** facilitating patient involvement in research activities and promoting innovation in cancer care.
9. **Quality Assurance and Standards:** setting quality standards for cancer care and supporting CCCs in meeting these standards.
10. **Monitoring and Evaluation:** assessing the impact and effectiveness of initiatives and making data-driven improvements.

Actions

The Working Group (WG) will be actively engaged in various activities to fulfill its mission and objectives. These activities contribute to promoting patient empowerment, enhancing patients involvement, and improving cancer care and research outcomes. Key proposed actions are:



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1. Conducting Awareness Campaigns on Adverse Reactions:

- Initiating campaigns to educate patients, caregivers, and the general public about cancer prevention, new cancer treatments, potential adverse reactions to cancer treatments. These campaigns aim to enhance awareness and preparedness.

2. Coordinating Support Groups for Survivors:

- Establishing and coordinating support groups for cancer survivors, providing a platform for shared experiences, emotional support, and valuable insights into survivorship.

3. Participation in Hospital Boards:

- Advocating for the inclusion of patient representatives in hospital boards, ensuring that the patient perspective is considered in decision-making processes related to cancer care within Comprehensive Cancer Centers/Cancer Centers.

4. Organizing Awareness Campaigns on Prevention:

- Planning and executing campaigns focused on preventive measures, emphasizing early detection, healthy lifestyle choices, and awareness of risk factors. These campaigns aim to reduce the incidence of cancer through proactive measures.

5. Facilitating Patient Education Workshops:

- Organizing workshops to educate cancer patients, their families, and caregivers on various aspects of cancer care, treatment options, and available supportive care services. These workshops aim to empower individuals with knowledge for informed decision-making.

6. Creating Interactive Webinars on Survivorship Care:

- Hosting webinars focused on survivorship care, featuring experts and survivors to discuss post-treatment challenges, long-term care strategies, and ways to enhance the quality of life for cancer survivors.

7. Engaging in Public Policy Advocacy:

- Participating in advocacy efforts to influence public policies related to cancer care, funding, and research. Collaborating with stakeholders to advocate for patient-centric policies at both national and European levels.



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8. Implementing Wellness and Rehabilitation Programs:

- Introducing programs that focus on the overall well-being of cancer patients and survivor, including physical rehabilitation, mental health support, and wellness activities, to improve the holistic care provided to patients.

The above proposed actions align with the broader goals of the Working Group, reinforcing its commitment to patient-centric approaches, collaboration, and holistic improvement of cancer care and research. Moreover, these actions contribute to the comprehensive approach of the Working Group, emphasizing education, advocacy, research, and support across various facets of cancer care and survivorship. Once the proposed Action Plan is approved, it will be reviewed and the proposed actions will be included in a concrete time plan.