



European Cancer
Patient Coalition



Annual Report 2022

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Correspondance

European Cancer Patient Coalition

Avenue des Arts 6

1210 Brussels

Belgium

info@ecpc.org

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1. The European Cancer Patient Coalition

Established in 2003, the European Cancer Patient Coalition is the voice of the European cancer patient community, uniquely representing the interests of all cancer patients from the most common to the rarest forms of cancer. It was set up to:

- represent the views of people with cancer in the European healthcare debate;
- enable and empower people with cancer by educating them about cancer and advocacy skills;
- provide a forum for Europeans with cancer to exchange information, best practice examples and share concerns on their national cancer care policies.

With an increasing focus on cancer at the EU level, it is all the more important for the perspectives of people living with cancer to be included in all EU projects, initiatives, policies, that may directly or indirectly affect them.

The European Cancer Patient Coalition derives its mandate to speak with “one voice” for all people with cancer from its wide membership and its democratic structure.

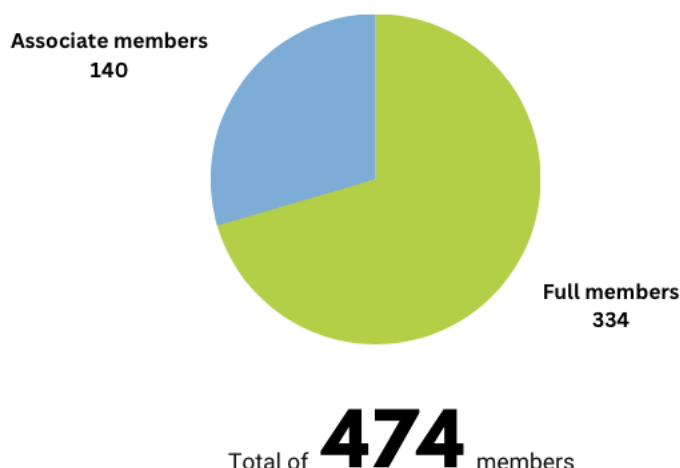
The motto of the European Cancer Patient Coalition is: “Nothing about us, without us!”

1.1 Mission

- To empower people with cancer through the dissemination of information
- To foster collaboration and co-operation among cancer patient organisations through joint activities
- To ensure that state-of-the-art cancer care practices are shared across the European Union
- To make cancer a priority for action in the European health policy agenda
- To have an active role in shaping European and national healthcare policies
- To contribute to change or create European and national laws to meet the needs of people with cancer
- To call for the people with cancer to be included in cancer research

1.2 European Cancer Patient Coalition by the numbers

ECPC Membership at a glance



2. General evaluation of the year 2022

The main objective of the 2022 Action Plan was to continue to represent the voice of patients with cancer at the European Union-level. With the launch of Europe's Beating Cancer Plan in 2021, the EU decided to focus on tackling cancer, a complex group of diseases, at the supranational level. 2022 was the year where the implementation of the ambitious Action Plan and projects stemming from the Mission on Cancer started.

Representing the voice of patients with cancer at EU level, ECPC focused its activities on ensuring that patient perspective is reflected in 25 EU projects and various policies and initiatives focusing on cancer and health. Additionally, ECPC represented the voice of patients

at external meetings, including the meetings hosted by the Czech Presidency and various events at the European Parliament, and other stakeholder events that were crucial towards shaping policies at EU level.

The European Cancer Patient Coalition worked tirelessly to ensure that the needs of patients with cancer are included in all healthcare initiatives and policies created at the EU level.



3. Policy & Advocacy

The European Cancer Patient Coalition (ECPC) has been active in 2022, representing the voice of people living with cancer in relevant policy initiatives.

Please find below the brief summaries of key initiatives ECPC was a part of in 2022:

1. ECPC stands with Ukrainian cancer patients and people - 28th February 2022

In February 2022, the European Cancer Patient Coalition published a communication to strongly condemn the invasion of Ukraine by the Russian armed forces. ECPC considers this invasion a direct threat to democracy that puts at risk the lives of millions of Ukrainian citizens, including cancer patients and their families. The aim of this communication was to show our support to the Ukrainian ECPC Members and ECPC Member organisations in Romania and Poland, who tried to offer their support with all the available resources they had.

2. The EU Challenge Cancer Parliamentary Intergroup calls for European Institutions to support the establishment of the EU Cancer Survivorship Day – July 2022



In a letter sent on July 6, 2022 to the European Parliament President, Roberta Metsola, European Commission President, Ursula von der Leyen, and the EU Commissioner for Health and Food Safety, Stella Kyriakides, 63 MEPs from several political groups, the signatories asked the two Institutions to endorse the

establishment of an Annual European Cancer Survivorship Day. On this occasion, the Challenge Cancer Parliamentary Intergroup drew attention to the 20 million European cancer survivors, who are often faced with lifelong struggles.

3. Joint statement on the protection of immunocompromised patients during the COVID-19 pandemic

In July 2022, ECPC, the European Kidney Health Alliance (EKHA), the European Society for Organ Transplantation (ESOT) and Union Therapeutics published a joint statement aimed at raising awareness on the fact that preventive action through SARS-CoV-2 vaccines is suboptimal for immunocompromised patients (i.e., cancer patients), and treatment may come too late to avoid severe consequences. For this reason, the above-mentioned organisations and ECPC called on the European Commission, Parliament, and the Council to fully integrate the systematic protection of immunocompromised patients in their response and preparedness efforts against the current and future health crises such as the next infectious disease outbreak. Only through a long-term and systematic approach with a particular emphasis on prevention against infections, the EU will be able to deliver a truly equitable health strategy to protect all its citizens.

4. ECPC attends de Expert Conference on Oncology hosted by the Czech Presidency of the Council of European Union on 13-14 July in Brno, Czech Republic



ECPC was honoured to be the only patient organization to have been invited at the Expert Conference on Oncology “Modern Cancer Control: Saving Lives through Smart Solutions” organized by the Czech Presidency of the Council of the European Union on 13-14 July in Brno, Czech Republic.

On this occasion, ECPC, represented by President Francesco de Lorenzo and Senior EU Affairs Manager Adela Maghear, emphasized the need for cancer patients’ organizations being involved in the process of establishing Comprehensive Cancer Infrastructures (CCIs) at the EU level and the importance of patients being at the centre of the digital momentum.

The outcome of this high-level meeting was a Call to Action that came to reaffirm the strong commitment of all official delegates on the EU fight against cancer.

ECPC has brought its’ valuable contribution to the final content of this Call to Action, in order to strengthen the need for a patient centric approach and the crucial role of patient organizations to accelerate progress and overcome obstacles in meeting the EU flagships initiatives.

ECPC’s contribution to the final document included the following key aspects:

- The need for CCIs to consider defining an outreach area for each CCI, as well as the range and scope of services in the areas of prevention, cancer screening and diagnosis treatment, supportive and palliative care, survivorship, research,

- education and patient involvement, monitoring and evaluation of the quality of care;
- The urgency to develop CCI in each Member State and of at least one CCI per 5 million inhabitants in larger countries and ensure access to multidisciplinary oncology services to all cancer patients;
- The integration of the recommendations and goals of the Europe's Beating Cancer Plan and EU Cancer Mission in the concept of the CCIs Network to ensure that innovations reach all patients across Europe;
- The European Commission should support Member States to drive forward the actions required to meet the ambitions set by EU Beating Cancer Plan, monitor closely the uptake at the national level and the progress towards the achievement of the agreed goals;
- The need for sustainable, resilient and value-based health systems that are driven by high-quality, comparable data. Such health systems consider the outcomes that matter to people and patients and are able to collect and analyse them in real time;
- The European Union should support Member States to invest more in health literacy and digital health literacy of patients and health care professionals.

ECPC President Francesco de Lorenzo discussed with the Czech Health Minister Vlastimil Válek, the Czech Deputy Minister of Health Jakub Dvoracek, the WHO Director of the Division of Health Programmes Nino Berdszuli, and the European Commission Team Leader of the Cancer Taskforce Matthias Schuppe, the final content of the Call to Action that will serve as a background document for further discussion during the Informal Meeting of the Ministers of Health that will take place on 6-7 September 2022 in Prague.

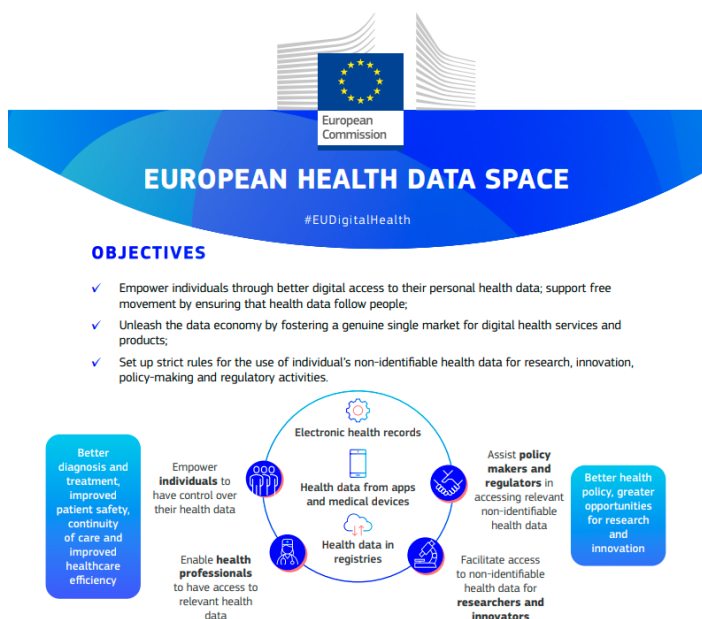
ECPC stressed on the need to introduce tests for early detection of lung and prostate cancers as part of the national screening programmes and that patients' preferences should be considered in the creation of the CCI network to be achieved by 2025.

5. ECPC meets with the Alliance of Women with Breast Cancer in Brno, Czech Republic - 13-14 July 2022



During ECPC's participation in the Expert Conference on Oncology hosted by the Czech Presidency of the Council of the European Union (Brno, 13-14 July 2022), ECPC President, Francesco de Lorenzo, met with the Representative for the Alliance of Women with Breast Cancer at the ECPC and at Europa Donna, Marta Kostrová, and the Director of the Alliance, Štěpánka Pokorná and areas for further collaboration were discussed.

6. The EU Health Coalition calls for ENVI Committee to be given shared competence on the European Health Data Space (EHDS) file (18 July 2022)



The publication in May 2022 of the European Health Data Space (EHDS) by the European Commission was an important step towards a more patient-centric, interoperable, safe, and reliable environment for health data. Therefore, considering that 'EHDS should be set up with a clear health perspective in mind, recognizing the specificities of the health sector, to meet the objectives of strengthening cooperation, improving research, and ensuring more equality for patients' on 18 July 2022, at the

initiative of ECPC, the EU Health Coalition sent a letter to the EU Parliament President Roberta Metsola calling that the Committee on Environment, Public Health and Food Safety (ENVI) should be given shared competence within the European Parliament with the Committee on Civil Liberties, Justice and Home Affairs (LIBE), on this legislative file to ensure 'a patient-focused approach to the debate around the Regulation on the EHDS – inclusive of their needs, preferences, and goals – and would consider the views of healthcare professionals and the wider health community'.

7. ECPC participation at the pre-ESMO LUNGEVITY event 'Preserving Patient Access to Clinical Trials: Aligning on Near-term Strategies for Multiregional Clinical Trial Initiation' (7 September 2022)



On September 7th 2022, Dr Adela Maghear, ECPC Senior EU Affairs Manager, was invited speaker at the pre-ESMO event by the US non-profit patient organisation LUNGEVITY entitled "Preserving Patient Access to Clinical Trials: Aligning on Near-term Strategies for Multiregional Clinical Trial Initiation". Dr Maghear spoke about the impact that the new EU In Vitro Diagnostic Medical Devices Regulation (IVDR) has on patient access to these devices and the clinical trials involving their use.

The new IVDR introduces new requirements for the authorisation of clinical trials involving in vitro diagnostics (IVDs). However, the regulatory infrastructure necessary to meet these requirements will not be in place for at least another five years, which may lead to significant delays in the initiation of clinical trials and even the exclusion of patients from certain countries from these trials.

Given the fact that the lack of these devices on the market can lead to the death of patients who depend on them (as in the case of cancer patients), Dr Maghear proposed

a meeting in Brussels, in the presence of the European Commission, to discuss solutions for a direct cooperation between healthcare professionals, healthcare institutions, manufacturers and national competent authorities for medical devices.

8. The frontline oncology workforce unites to reduce the burden of cancer before it hits: PrEvCan



On September 9, 2022, ESMO, the leading professional organisation for medical oncology, together with EONS, a pan-European membership organisation for cancer nurses, announced the launch of the ground-breaking, Europe-wide “Cancer Prevention Across Europe” campaign

(PrEvCan) aimed at reducing the burden of cancer. The announcement was made at the opening press conference of the ESMO Congress 2022 in Paris, at which ECPC President, Francesco de Lorenzo was among the invited speakers.

On this occasion, Francesco de Lorenzo stressed on the fact that the contribution and collaboration of ECPC, by sharing the campaign messages with more than 470 members across Europe, will help to strengthen and widely disseminate the importance of healthy living. The PrEvCan campaign also represents an excellent opportunity for collaboration among cancer patient organisations, physicians and oncology nursing societies in Europe, who are at the frontline of cancer care, to push for preventative measures that will reduce the burden of cancer.

The PrEvCan campaign was initiated and led by EONS with ESMO as key partner, alongside the European Cancer Patients Coalition (ECPC) and more than 50 other international and national organisations. The campaign is based on the European Code Against Cancer (ECAC), which sets out 12 recommendations ranging from physical activity and dietary guidelines all the way to tobacco use and second-hand smoke. Over a period of 12 months starting from October 2022, each month has been dedicated to promoting one of these recommendations and highlighting the scientific evidence supporting it, with the dual objective of increasing awareness of how to prevent cancer among the public and of providing healthcare professionals with a more comprehensive toolkit for communicating the importance of cancer prevention effectively.

9. ECPC participation at the 5th Gago Conference 2022 - October 6, 2022



The 5th Gago Conference on European Science Policy was held on October 6, 2022, in Heidelberg. Since its first edition, held in Porto (Portugal) on 14th February 2018, ECPC has been an active part of this forum, mitigating to include patients in policy and research and to empower them in becoming co-creators of their own health.

The conference was an international platform to debate on emerging issues of research and innovation policy in Europe.

The theme of 2022 was “Cancer research: Society at the frontiers of knowledge.” The conference brought together leading representatives from academic, business, social, culture and government sectors worldwide to present and discuss current and future issues of critical importance for European science and technology, including their impact to foster social and economic development and shared prosperity both at home and abroad.

On this occasion, ECPC President and Board Member of the European Academy of Cancer Sciences (EACS), Francesco De Lorenzo, delivered a speech on “Emerging developments in European cancer policy”. De Lorenzo emphasized on the need for advocacy patients to be co-creators of research projects in the field of quality of life, concerning health related quality of life aspects. In this context, he pointed out the principles of successful patient involvement in cancer research presented by the trio EU Council Presidency - Germany, Portugal, and Slovenia. While focusing on patients’ needs and values, ECPC is a link between stakeholders that advocates for better collaboration between researchers and patients, allowing patients to make use of their experience towards effectively translating research into clinical practice.

The take aways of this high-level event were summarised in the article entitled “Engaging European society at the forefront of cancer research and care - How discussions at the 5th Gago Conference on European Science policy led to the Heidelberg Manifesto” published in the Molecular Oncology journal.

10. ECPC participated at the European Society of Surgical Oncology event Time for Change: Addressing the value of surgical oncology

In October 2022, ECPC President Francesco de Lorenzo spoke at the European Society of Surgical Oncology Conference entitled ‘Time for Change: Addressing the value of surgical oncology’.

SURGICAL ONCOLOGY
Shedding light on an essential component of cancer care

What is the value of surgical oncology as part of cancer care?

Surgical oncology is critical to ensure high quality cancer care

- 80%** of cancer patients will require surgical intervention during the course of their disease
- 45m** surgical procedures will be needed worldwide per year by 2030
- <25%** of cancer patients actually receive safe, affordable or timely surgery across the globe
- 2.7million** years of life lost to disability worldwide

Surgical oncology has multiple roles in cancer patients

- Surgical resection remains the best chance of cure for solid cancers when diagnosed early
- Reduces the risk of getting cancer as part of hereditary syndromes
- Diagnoses and stages cancer
- Treats locally advanced cancer & metastatic disease
- Preserves quality of life and palliates symptoms

Surgical oncology can cure the most prevalent and deadly cancers, including:

- Breast
- Skin
- Lung
- Liver
- Colon

Surgical oncology is cost-effective

For the majority of non-metastasised solid tumours, surgery is the most cost-effective treatment with the highest value for money

Costs of Cancer Surgery vs Costs of Systemic Therapy

2000 2020

Surgical oncology is keeping pace with innovation

Research is continuing to refine surgical oncology technologies, techniques and processes to allow more patients to benefit from effective, safe, minimally invasive and cost-effective treatment

Innovations such as robotics, functional imaging and Artificial Intelligence (AI) are opening new horizons to enhance cancer surgery

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www.essoweb.org info@essoweb.org @essonews ESSO

The event was hosted by MEP Cristian Busoi (Romania, EPP), Chair of the Challenge Cancer Intergroup. Relevant stakeholders including EU policy makers and representatives from European cancer organisations, together with ESSO opinion leaders gathered to discuss the crucial role played by surgical oncology in cancer care to reduce the increasing cancer burden and to ensure a patient-centered care system in Europe.

The main takeaway on the meeting was that surgical oncology is the first pillar of clinical oncology. Therefore, it must be recognised as an individual medical specialty.

The ESSO policy event was endorsed by the EP Challenge Cancer Intergroup and the European Cancer

Patient Coalition (ECPC).



In his speech, De Lorenzo stressed on the need for a call to action letter, cosigned by MEPs relevant in the field of health policy, to call on the European Commission to recognize surgical oncology an individual medical specialty. This idea was welcomed by MEP Cristian Busoi. Therefore, ECPC worked in close collaboration with ESSO to draft this letter and to reach MEPs from different political groups to sign it.

11. ECPC participation at the “Better Breast Cancer Care for a Better Life – A call to action”, European Parliament, 12 October 2022

On October 12, 2022, the Transforming Breast Cancer Together (TBCT) initiative, where ECPC is a partner, organized the event entitled “Better Breast Cancer Care for a Better Life – A call to action”. The event took place in the European Parliament and was chaired by MEP Frances Fitzgerald (EPP, Ireland).

This event marked the launch of the call to action with the same title focused on screening, early diagnosis, access to care and quality of care that was aimed at

highlighting the importance of timely implementation of the Europe's Beating Cancer Plan.



On this occasion, Dr Adela Maghear, the ECPC Senior EU Affairs Manager, who was among the invited speakers, stated that the EU Institutions should support Member States by investing in the development and uptake of early detection tools, diagnostic and treatment solutions by developing EU-funded research initiatives and partnerships and by leveraging the European Health Data Space (EHDS) to create an EU harmonised registry to

collect breast cancer data, including metastatic breast cancer data. When talking about the importance of quality of care, she also added that the EU Institutions should support the establishment of certified Breast Centres for all European breast cancer patients to be treated, including metastatic breast cancer patients and ensure that the revised EU Cross Border Healthcare Directive offers a functional framework that allows cross-border collaboration, access to medicines, therapies and quality medical services and prescriptions' exchange between countries.

12. ECPC participates at the World Cancer Congress 2022, October 18-20, in Geneva, Switzerland



ECPC was honored to organize a "Precision Oncology and Biomarkers: Opening New Therapeutic Avenues for Cancer Patients" session at the Union for International Cancer Control (UICC) World Cancer Congress 2022. The session, moderated by ECPC President Francesco de Lorenzo, featured expert panelists including Dr. Nicola Normanno, Dr. Alik Stathopoulou, and Nicolas Philippou.

During the session, the panel discussed the importance of the relationship between precision oncology and biomarkers, highlighting how biomarker knowledge can benefit cancer patients. However, the integration of biomarkers into clinical practice faces barriers in EU member states, leading to inequalities in cancer care.

The key message of the session emphasized the need for coordinated efforts from stakeholders at both European and national levels to enhance access to and quality of biomarker testing. Dr. Nicola Normanno presented precision oncology's current and future landscape, highlighting the increasing number of precision medicines that require biomarker testing for regulatory approval. Nonetheless, the limited availability of biomarker testing in several European countries impedes access to precision medicines. Barriers such as infrastructure and organization deficiencies, delayed reimbursement

approval for new tests, budget constraints, and low participation in quality assessment programs were identified.

The session concluded by emphasizing the necessity of unified and collaborative approaches in cancer care to achieve better outcomes and broader advancements in biomarker access and quality.

13. ECPC collaborates with GAMIAN on a joint initiative Comorbidity of Cancer and Depression (October 26, 2022)

Within the context of Europe's Beating Cancer, a project was formed as a joint initiative between GAMIAN-Europe and the European Cancer Patient Coalition (ECPC). Within this context, ECPC supported GAMIAN-Europe in the organization of a virtual workshop on October 26 2022 with patients and carers about the Comorbidity of Cancer and Depression and its effects on patients and in the dissemination of a relevant survey. The objectives of this project were to:

- Raise awareness on the issue of depression as a cancer co-morbidity;
- Gather in-depth patient accounts on the issue of this comorbidity (for both patients that had either depression or cancer diagnosed first);
- Gather information from relevant stakeholders such as patients, clinicians, researchers, and EU and national policymakers, regarding the challenges of this co-morbidity;
- Encourage dialogue between patients, clinicians, and other stakeholders as a basis for policy recommendations for EU and national policymakers.

As a result of the action, a report will be published detailing the findings of the workshop and the survey to seek the experiences of patients with comorbid cancer and depression and professionals working in the field.

14. Representing the patient voice at the Economist's 8th Annual World Cancer Series Europe - November 8 -9 2022

ECPC President, Francesco de Lorenzo, was invited as speaker in The Economist's 8th Annual World Cancer Series Europe. The focus of the 2022 conference, that took place in Brussels on 8-9 November, was "innovation, equity and excellence". The event aimed at identifying strategies to accelerate innovation, reduce inequities across cancer control in Europe, and to build towards universally excellent cancer control and cancer outcomes across the continent.

De Lorenzo, invited at the panel "Which novel biomarkers are changing patient outcomes?", took the opportunity to emphasise the long-term work of ECPC in the field of personalised medicine and biomarkers. He addressed the report "Unlocking the potential of precision medicine in Europe" (Feb.2021), published by ECPC in collaboration with IQN Path and EFPIA, that was based on the results of a survey on access to biomarkers conducted in 2020 in the 27 EU Member States and UK.

15. ECPC White Paper Launch Event: “Future consideration for CAR-T therapies: A multi-stakeholder perspective”



On 28 November 2022, in an online event, ECPC launched the white paper “Future consideration for CAR-T therapies: A multi-stakeholder perspective”.

There is an ongoing search for therapies with improved outcomes, one of them is immunotherapy, such as Chimeric Antigen Receptor T-cells (CAR-T), which enhances the patient’s immune response capacity. CAR-T is an EMA and FDA approved cell therapy for the treatment of certain blood cancers and the approval was based on a ground-breaking clinical study reporting 83% complete remission after only three months of CAR-T treatment in patients who had received many unsuccessful rounds of traditional blood cancer therapy. In view of the foregoing, the ECPC white paper aimed to bring to light the

information available on the current situation of CAR-T therapies in term of accessibility, delivery, pricing, reimbursement, as well as ethics.

Even though CAR-Ts offer enormous promise, they also come with considerable scientific, clinical, logistical, policy and regulatory challenges. The main objective of this webinar was to introduce CAR-T modality among relevant stakeholders and to explore its potential benefits for cancer patients across EU member states.

16. The Challenge Cancer Intergroup calls on the EU Council to propose the necessary evidence- based steps to optimize lung cancer screening in Europe – November 2022



On November, 10, 2022, MEP Cristian Busoi (EPP, Romania) chaired the internal meeting of the Challenge Cancer Intergroup – “Towards strengthening lung cancer screening in Europe” – held in the European Parliament, organised in collaboration with the European Cancer Patient Coalition (ECPC). Several distinguished MEPs from different political groups have joined the meeting and

expressed their views on the future of lung cancer screening in Europe.

The debate was an in-depth, close-door discussion, on the Revision of the European Council Recommendation on cancer screening concluded during the Czech Presidency of the Council that proposed a new approach to support Member States increase the uptake of cancer screening.

In this context, the invited experts, Dr. Ugo Pastorino, Scientific Director of Thoracic Surgery of the IRCCS-National Cancer Institute Foundation in Milan and Prof. Giorgio Vittorio Scagliotti, Professor of Medical Oncology at the University of Turin, provided their experience and professionalism to shed light on the medical aspects of the Council Recommendation and, its impact on early detection, cancer care and the burden of cancer.

This meeting was a timely opportunity to explore some of the critical issues that have emerged from the revision of the Council's draft Recommendation in relation to lung cancer screening. The draft text proposed at that time defined evidence of low-dose tomography for lung cancer screening as preliminary whereas there is established evidence. Moreover, it did not provide sufficient clarity on the need to implement lung cancer screening in a phased manner including, among other factors, eligibility criteria, thus limiting its scope.

Furthermore, by neglecting the already existing scientific evidence on the benefits of early screening and leaving it up solely to the Member States to assess the necessity of cancer screening at national level, based on their resources and capacity, drives to the non-implementation of the EU Cancer Plan recommendations for cancer screening and will further deepen inequalities in access to cancer care in Europe.

Following the above-mentioned meeting, on 11 November 2022, The European Cancer Patient Coalition (ECPC) coordinated, in collaboration with the Challenge Cancer Intergroup, a call to action letter addressed to the Commissioner on Health and Food Safety Stella Kyriakides.

The letter entitled "Declaration on the EU Council Screening Recommendation on Lung Cancer" was written under the guidance of MEP Cristian Busoi, the Chair of the Challenge Cancer Intergroup, and was cosigned by 48 MEPs from different political groups who expressed their serious concerns about lung cancer as the leading cause of cancer deaths in Europe "not being treated as a public health priority nor with the urgency it requires at the policy level". The letter also included a clear demand from MEPs to the EU Council and Commission to ensure the extension of the European Council Recommendation on cancer screening to lung cancer by including a "standalone section on lung cancer screening with explicit recognition of the well-established evidence base", an aspect that was not fully acknowledged in the EPSCO conclusions of December 2022.

In response to this letter, in January 2023, Commissioner Stella Kyriakides sent a written reply to MEP Busoi, where she explained that she is fully aware of the "important challenge that lung cancer is posing both on patients and on healthcare systems". However, she would have preferred that the Council recommendation on cancer screening was more ambitious "when it comes to recognising the evidence base for lung cancer screening". But "the fact that we succeeded in maintaining lung cancer screening in the recommendations" is, nevertheless, an important achievement.

She confirmed the commitment of the EU Commission to support the Member States in implementing the Council recommendations through funding from the EU4Health Programme. In this sense, Ms. Kyriakides added that “the Commission has already dedicated substantial funding for screening under the work programmes 2021 and 2022 to the magnitude of EUR 38.5 million. In addition, following the adoption of the Recommendation, a further 38.5 million is planned under the work programme 2023 mainly to assist Member States with implementation of these new recommendations, including the development of European guidelines and Quality Assurance Schemes for the three new cancer sites (lung, prostate, gastric)”.

In her reply, the Commissioner acknowledged as well “the stigma that is often associated with lung cancer and its risk factors” assuring the MEPs that this aspect was included in the proposed recommendations on cancer screening.

Ms Kyriakides concluded by pointing out “the importance of primary prevention approaches including both non-legislative aspects such as health literacy, and legislative actions such as tobacco control” and confirming that “one major policy initiative for the next year is the upcoming proposal for a Council Recommendation on smoke-free environments.”

ECPC will continue its endeavor in raising awareness on the cancer patients’ needs, values and preferences in terms of early detection and expresses its willingness to continue its long-term collaboration with the European Parliament, Commission and Council in achieving what matters to cancer patients.

17. Health and life science to be recognized as the third strategic pillar for for a true EU Health Union

The EU Health Coalition is composed of 43 patient organisations (which include ECPC), EU research-oriented medical societies, industry organisations, healthcare providers, regional and local health authorities and other relevant stakeholders, who all share a common vision.

In November 2022, at the 3rd EU Health Summit: [Towards an EU Health Union](#), the EU Health Coalition has published its vision for European health, strengthened by a set of concrete recommendations and policy proposals to which ECPC contributed through its Senior EU Affairs Manager Adela Maghear.

The recommendations, which included 4 main pillars: digital transformation, health system integration, boosting research & innovation and access to innovation, supported the vision of the Coalition “for a Europe that takes a life-course approach to health – with a joined-up focus on health promotion, disease prevention and overall well-being – as well as on advancing the treatment, management, and cure of diseases”.

18. ECPC participation at the 'Onco-Roundtable – Lung and prostate cancer' held in Prague - 29 November 2022



The Onco-Roundtable conference held in Prague on November 29 focused on cancer prevention and treatment in the Eastern European Countries. Sixteen leading experts from across Europe spoke about early cancer diagnosis, innovative and

multidisciplinary approaches to coordinated care, both from a medical perspective as well as from a political point of view. Experts agreed that there are still large inequalities in prioritizing the fight against cancer and supporting preventive care between countries in Europe.

Adela Maghear, ECPC Senior EU Affairs Manager, was among the invited experts at this international event. In her speech, she stressed out that at the EU level there is political will to tackle the inequalities between Member States in access to cancer screening, which result in lower chances of survival due to late diagnosis of cancer. She welcomed the ambitious initiatives and recommendations set out in the EU Beating Cancer Plan, while pointing out that the barriers in implementing these targets are mainly at the national level.

19. White Paper: 'Digital Medication Management in Healthcare Settings: an opportunity for the European Union'



In November 22, 2022, ECPC published the White Paper 'Digital Medication Management in Healthcare Settings: an opportunity for the European Union' that the organisation co-authored with the European Health Management Association.

This White Paper outlines the Alliance for the Digitalisation of Medication Management in European Hospitals' calls for action, providing examples from across of the European Union of digitalisation of the pathway. The Calls for actions include:

- Implement digital systems in hospitals for the effective employment of the European Shortages Monitoring Platform.
- Enhance patient safety and hospitals' pharmaceutical systems resilience by digitalising hospital's medication management pathways.
- Support hospitals to scale up and update their IT infrastructure.
- Provide sustained funding to scale up digital medication management.

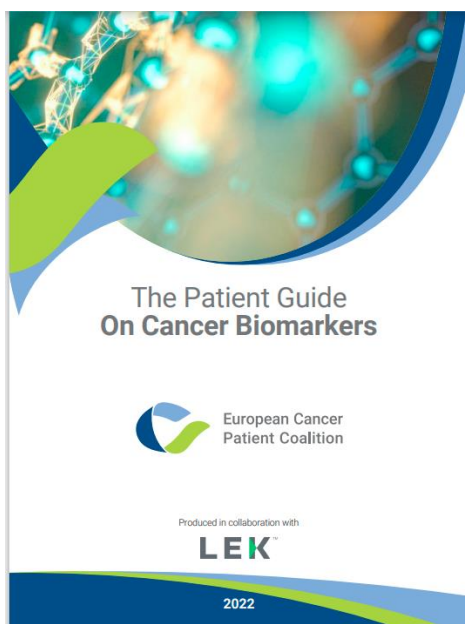
- Develop healthcare professionals' digital skills and provide trained experts to support change management in hospitals.
- Standardise and include medication treatment data from ambulatory care and hospitals in the European Health Data Space.

20. ECPC participation at 'I-Know-How' Campaign closing event (15 December 2022)



ECPC Senior EU Affairs Manager, Dr. Adela Maghear, was invited to speak on December 15, 2022, at the closing event of I-Know-How that took place in Gent, Belgium. The aim of the project was to support cancer patients and survivors to return to and / or maintain work by co-creating and piloting new services for employers, employees, medical professionals and job coaches.

The Patient Guide on Cancer Biomarkers



Cancer treatment is increasingly shifting towards precision oncology, an approach that systematically utilises patient/tumour data to inform personalised treatment decisions. With precision oncology, physicians can identify molecular characteristics of a patient's tumour and select a treatment that will be most effective at targeting that specific tumour subtype. The vision for precision oncology is transformative: to deliver superior outcomes for all cancer patients and ultimately reduce the suffering caused by cancer.

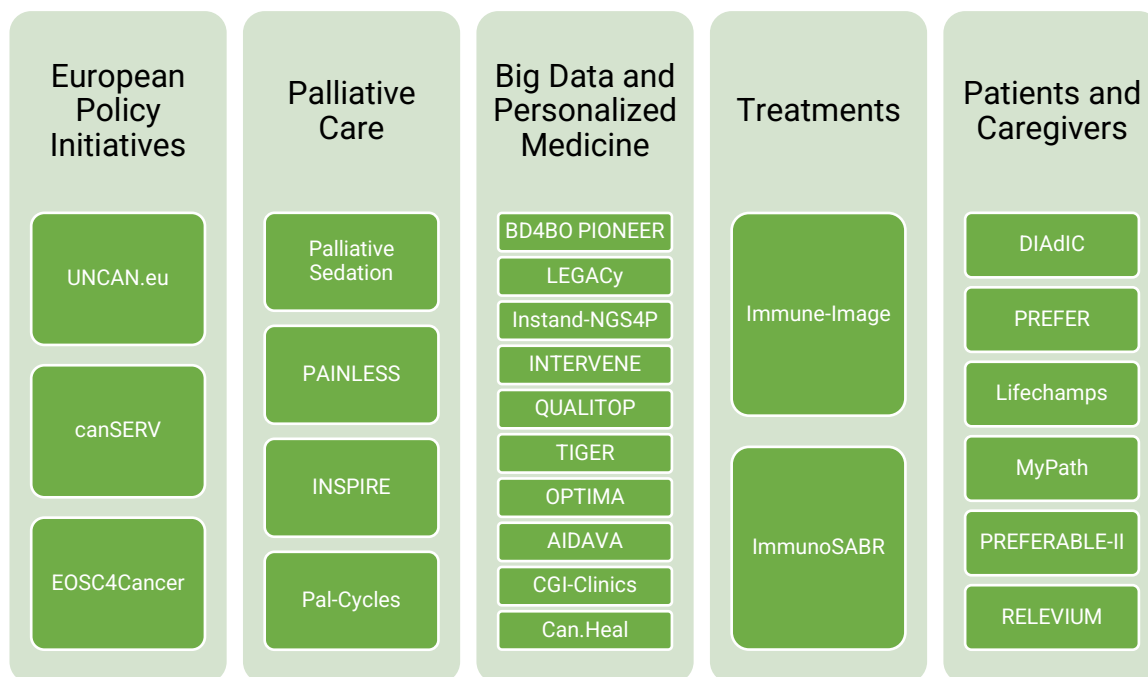
[The Cancer Biomarkers Patient Guide](#) has been initiated by the European Cancer Patient Coalition – ECPC as part of ECPC activities for awareness

raising on personalized medicine in cancer during its Personalized Medicine Month in November to assist patients, their family members and friends to understand better the cancer biomarker testing that may influence the decisions for their personalised medicine treatment. The Guide was prepared to offer concise information to patients, who will have cancer biomarker testing in view of receiving personalized medicine treatment. The Guide includes all basic information cancer patients, carers and families may wish to have handy in preparation of their medical appointments.

Cancer patients are invited to consult the Glossary to familiarize themselves with the terms used for cancer biomarker testing as well as the suggested questions to be asked to their healthcare team before and after cancer biomarker testing.

4. Health & Research

With the Mission on Cancer and Europe's Beating Cancer Plan, ECPC was involved in 25 EU Projects over the year 2022, representing the voice of people living with cancer.



a. European policy initiatives

1. UNCAN.eu - UNderstand CANcer



Consortium includes 29 core and advisory partners from 20 countries, with a total budget of 3M €.

Cancer remains the second leading cause of death in Europe and one of the greatest challenges facing the continent. Currently, 1.3 million people die from cancer every year across Europe and a new level of investment to better prevent, diagnose and treat cancer is recognized as an urgent need. The Coordination and Support Action (CSA) 4.UNCAN.eu started on September 1st, 2022, to prepare a blueprint for creating UNCAN.eu initiative. This program is one of the ten flagships of Europe's Beating Cancer Plan and one of the 13 recommendations of Cancer Mission, respectively.

The blueprint for UNCAN.eu includes the creation of a Federated Cancer Research data hub. Research programs will be included as use cases with two objectives: standardized

data contribution to the hub and involving researchers and patients from member states. Selected use cases will be ambitious, innovative, transdisciplinary, and highly competitive at the international level. The CSA emphasizes involving patients and citizens in defining use cases and collaborating closely with researchers. It aims to reduce disparities in cancer research among member states and collaborate with existing European Commission initiatives. The blueprint will propose a governance model for the Cancer Research Data Hub. UNCAN.eu ultimate goal is to generate significant new knowledge to save lives and improve the quality of life for cancer survivors.

Our role

✓ ECPC leads WP4 entitled "Patients and European Citizens in Cancer Research" with the main tasks of coordinating communication within "4.UNCAN.eu" and between the consortium and external stakeholders, communicating and disseminating the "4.UNCAN.eu" proposals and the final outcome to target audiences and key stakeholders as well as defining the role of patients in the UNCAN.eu initiative.

Our activities in 2022

✓ We developed a survey with the contribution of other partners of the project and distributed it to targeted audiences with the purpose of evaluating the level of scientific literacy among European citizens and identifying the cancer research priorities and expectations from the side of patients and the public so as to ensure that the final blueprint for UNCAN.eu will integrate the voice of cancer patients and EU citizens not currently directly affected by cancer.

✓ ECPC developed the "4.UNCAN.eu" communication strategy and dissemination tools (project's website, social media channels, press releases, newsletters, visual identity).

✓ We created a project-specific visual identity composed of a logo, colour palette, and templates for documents and presentations.

✓ ECPC issued a press release after the Kick-off meeting, and published an electronic Newsletter to communicate information about all aspects of the project.

<https://uncan.eu/>

2. canSERV - Providing cutting edge cancer research services across Europe



canSERV
providing cutting edge
cancer research services
across europe

The Consortium includes 19 European partners with a total budget of 14.8 M €.

European research infrastructures are valuable assets to drive efficient cancer research and strengthen the cancer innovation ecosystem in

Europe. The EU is now striving to further accelerate progress towards conquering cancer

in the coming decades. However, to achieve this, the European research community, its industry, and European citizens need to have the right tools to contribute to this goal. The mission of the canSERVs project is to make cutting-edge interdisciplinary and personalized research services available to the cancer research community throughout the EU, as well as to enable innovative R&D projects and promote precision medicine for the benefit of patients across the continent. canSERV brings together world-class European life science research infrastructures that collectively not only cover all aspects along the development pipeline for oncology but is also capable of interconnecting these technologies providing users a guidance for navigating them through the entire translational value chain. Through a united user-intuitive transnational access where a united catalogue of oncology services will be offered, our users will have access to a comprehensive service portfolio.

ECPC brings the patient's perspective to ensure that the project adequately reflects the concerns and perspective of cancer patients. Additionally, ECPC's active participation within canSERV guarantees that the available information is viewed holistically, from the point of prevention to that of survivorship, by providing a portfolio of tools that can be implemented to address the social sustainability of the consortium activities.

Our role

- ✓ ECPC co-leads WP11, entitled "Socio-economic dimensions and public health measures", ensuring that the available information is considered holistically, from the point of prevention to the point of survival, providing a portfolio of tools that can be applied in addressing the social sustainability of the consortium's activities.
- ✓ ECPC was actively involved in the activities of WP5 'Support to planning and design of complex trials', in order to bring the patients' perspective to selected clinical trial protocol so that their feedback can be embedded in the design of the clinical research proposal from the start.
- ✓ ECPC participated in WP12 'Training, Outreach & Stakeholder Engagement' to ensure that the canSERV project is supported and enhanced by a comprehensive communication strategy and stakeholder engagement programme, which primarily addresses academic and industrial users of the cancer community but also engages the public.

Our activities in 2022

- ✓ ECPC contributed to the development of the first version of the draft catalogue of ELSI services available for cancer research and defined the socioeconomic aspects of the project by providing information on available representative applications and patient-oriented services.

<https://www.canserv.eu/>

3. EOSC4Cancer - A European-wide foundation to accelerate Data-driven Cancer Research



Consortium includes 29 partners from 13 countries with a total budget of 7.8 M €.

cancer

Cancer research deals with diverse data sets, including clinical variables, medical images, genomics, experimental models, drugs, and clinical outcomes. From small-scale studies to large scale initiatives and clinical trials, data has been generated and collected providing an unprecedented stream of information. It is now time to connect this data and make it accessible to the research community.

Based on existing infrastructure, international standards and open services, EOSC4Cancer will develop a coherent infrastructure for the exploitation of cancer research data. It will make cancer genomics, imaging, clinical, environmental and socio-economics data accessible using and enhancing existing federated and interoperable systems for securely identifying, sharing, processing and reusing cancer data across borders, and it will build them via community-driven analysis environments.

Our role

- ✓ ECPC contributes to WP6 entitled 'Dialogue with patients, researchers, and EU initiatives to shape project execution, outcomes, and long-term alignment.
- ✓ ECPC participates in the Stakeholder Forum, which will be set up as a mechanism for stakeholders to shape, comment on ongoing developments in the project and respond to technology developments. More specifically, ECPC will ensure the dialogue with the patients regarding the shape of the outcomes and lines of the project. Help to identify the challenges related to cancer data services and the patient's needs. ECPC will contribute to enforcing patient engagement and improve the trust, transparency, and bias related to AI use in cancer diagnosis and treatment.

Our activities in 2022

- ✓ ECPC participated in the kick-off meeting which took place in Barcelona on September 28- 29, 2022.
- ✓ ECPC attended WP6 monthly meetings on communication and dissemination of the project.
- ✓ ECPC has been represented in the Project Execution WG.

<https://eosc4cancer.eu/>

b. Palliative care

4. Palliative sedation - The use of proportional palliative sedation for the relief of refractory symptoms: an international multicenter study



Consortium includes 10 partners from 8 countries, with a total budget of 4 M €.

The increasing number of cancer patients with refractory symptoms who fail conventional treatments necessitates the use of palliative sedation (PS), which is the intentional reduction of consciousness at the end of life. However, PS is too often limited to continuous deep sedation and is mistaken for hastening death.

The Palliative Sedation project aims to test the concept of proportional PS, where sedatives are titrated to the point of symptom control, with the goal of improving the patient's overall comfort. The project investigates current practices and guidelines, as well as conducts clinical study into PS, measuring patient comfort as the primary outcome. Furthermore, the Palliative Sedation project is formulating recommendations for an updated framework for the use of sedation in palliative care and working towards producing educational programmes programme and an e-book, and helping organise a policy workshop for further development and implementation, along with a closing conference to support the final dissemination of project results.

Our role

ECPC contributes to support tailored communication to the primary target group of cancer patients and their families.

Our activities in 2022

✓ ECPC has participated in the meetings of the communication team in this project.

<https://www.palliativesedation.eu/>

5. PAINLESS - Pain relief in palliative care of cancer using home-based neuromodulation and predictive biomarkers



PAINLESS
Pain Relief in Cancer

Consortium includes 19 partners from 10 countries, with a total budget of 4 M €.

services

Key words: Horizon Europe, Health policy and

Unfortunately, more than 50% of cancer patients experience pain before they die. Although most can be treated with drugs, a proportion of patients show a poor response to them or have serious adverse effects. Non-pharmacological interventions, such as neurosurgical procedures, have proven to be effective, however these alternatives are

not the preferred option for treating cancer pain due to their high cost, risk, invasiveness and not always proven efficacy. PAINLESS addresses a core component of pain relief, by using an innovative, evidence-based approach. The objective of the project is to adapt and implement a novel, cost-effective, home-based intervention based on neuromodulation to reduce pain and improve quality of life of cancer patients with chronic pain. In particular, PAINLESS will develop a customised web portal to share knowledge and to improve management of the patients; perform techno-economic analyses and Health Technology Assessment of the solution and analyse the possibilities of implementation in different European healthcare systems.

Our role

ECPC's role primarily focuses on Work package 6 – the activities for communication and dissemination of the results. The main aim of this WP is to design, manage and deliver the dissemination and communication plan for the project, to increase societal awareness and outcomes. We support the exploitation of results and undertake an ambitious dissemination and communication strategy.

Our activities in 2022

- ✓ ECPC participated in communication and dissemination meetings with the intent to design goals and set up processes how to achieve them.
- ✓ ECPC contributed into the coordination part via meetings participation to provide smooth project implementation.

<https://palliativeprojects.eu/painless/>

6. INSPIRE - Integrated Short-term Palliative REhabilitation to improve quality of life and equitable care access in incurable cancer



Consortium includes 10 partners from 7 countries, with a total budget of 2,44 M €.

Disability is a poorly recognised and undertreated consequence of incurable cancer. It can occur as a result of the disease, its treatment, and related symptoms and syndromes. Over time, loss of function results in people not being able to continue with valued roles and routines, to manage usual household and social activities, and to selfcare. Disability reduces quality of life and well-being and increases burden on informal and formal carers, demand for hospital or nursing care. INSPIRE overall objective is to test the clinical and cost effectiveness of an integrated short-term palliative rehabilitation intervention to improve function and quality of life in people affected by incurable cancer and reduce the burden of care for their families. This person-centred trial, if positive, could result in a scalable and equitable intervention that reduces symptom burden and disability and increases social participation, leading to

better quality of life. The intervention can be adapted and integrated into different health systems using existing staff and services, with little or no additional cost. The INSPIRE consortium brings together leaders in palliative care, oncology and rehabilitation with complementary expertise in health services research, trials of complex interventions, mixed method evaluations, statistics and economics.

Our role

ECPC provides support to WP8 (Dissemination & Exploitation) as part of the communication team.

Our activities in 2022

- ✓ ECPC participated in the kick-off meeting in Lyon.
- ✓ ECPC contributed to the development of the interventions and coordination of the main trial.
- ✓ ECPC attended regular meetings to ensure the dissemination and exploitation of the study.

<https://palliativeprojects.eu/inspire/>

7. Pal-Cycles - PALliative Care Yields Cancer wellBeing Support



Pal-Cycles

Consortium includes 10 partners from 9 countries, with a total budget of 4.5 M €.

Many patients with advanced end-stage cancer leave the hospital with

uncertainty about how to proceed with their treatment and aftercare. Communication between healthcare professionals in different settings is often not optimal, resulting in poor continuity and coordination of care, negatively impacting quality of life and increasing avoidable hospital admissions. Unfortunately, palliative care teams are often not involved in hospital discharge, which can hinder personalized and holistic care planning focused on the specific needs of individuals requiring palliative care. PAL-CYCLES is a transitional palliative care programme for patients with advanced cancer, adaptable to local cultures and healthcare systems. The programme contains an intervention aiming for a smooth transition from hospital care to community care, consisting of: (1) identification of a patient with palliative and supportive care needs; (2) compassionate communication towards the patient and their family; (3) a collaborative multidimensional care plan and follow-up; (4) periodic evaluation of the care plan; (5) identification of the terminal phase (if there) based on the periodic evaluations, with appropriate intensification of care and end-of-life talks. The PAL-CYCLES programme will facilitate patient-centred communication and continuity of palliative cancer care in the community care setting, reducing unplanned hospital admissions and improving quality of life for patients with advanced cancer at the end of life.

Our role

ECPC contributes in WP1 (Development and local adaptation of the PALCYCLES framework intervention) for the development, co-design and local adaptation of the PALCYCLES intervention. In WP4 (Barriers and facilitators for planning and developing the PAL-CYCLES intervention through multi centre case study method), to participate in the literature review of policy documents on transitional care and in WP6 (Dissemination and exploitation), where the association provides a network for the dissemination, exploitation and communication of the project and its results.

Our activities in 2022

- ✓ ECPC attended the kick-off meeting of the project in Amsterdam.
- ✓ ECPC contributed with the dissemination and exploitation of the project.

<https://palliativeprojects.eu/palcycles/>

c. Big data and personalized medicine

8. BD4BO PIONEER - Prostate cancer diagnosis and treatment enhancement through the power of Big Data in Europe



PIONEER

Consortium includes 32 partners from 9 countries, with a total budget of 6 M €.

Prostate cancer is the second leading cause of cancer in men in Europe and, currently, there is a need for addressing a better definition of the disease across all stages, improving patient's stratification at diagnosis, and standardising of outcomes based on real life data. PIONEER is one of the BD4BO disease-specific projects and serves as the European Network of Excellence for Big Data in Prostate Cancer. The project is using big data to address key knowledge gaps related to screening, diagnosis and treatment of prostate cancer by standardising and integrating already existing big data in clinical trials and electronic health records from diverse populations of prostate cancer patients across different stages of the disease into a single, innovative data platform. PIONEER is working for meaningful improvement in clinical practice, improved health outcomes and increased health-system efficiency by providing evidence-based data, so patients can benefit from the best possible care.

Our role

ECPC participates in WP7 (*Dissemination and communication*) to ensure that the patients engage in their disease management, thus leading to better treatment adherence and improved Quality of Life.

Our activities in 2022

ECPC promoted the project and its goals through our wide network and supported communication towards the public.

<https://prostate-pioneer.eu/>

9. LEGACy - CELAC and European consortium for a personalized medicine approach to Gastric Cancer



legacy

CELAC and European consortium
for a personalized medicine
approach to Gastric Cancer

Consortium includes 11 partners from 9 countries, with a total budget of 3.5 M €.

Gastric cancer is the third leading cause of cancer death in both sexes worldwide. Despite its high incidence, strategies to improve prognosis in locally advanced cases have not improved and urgent intervention is needed. Most of the current international studies and databases on advanced-stage gastric cancers are mainly based on Asian populations, while the tumour biology and genome of EU and CELAC countries are poorly understood. LEGACy project aims to improve gastric cancer outcomes by applying personalized medicine at the three levels of prevention: primary, secondary, and for improving outcomes at the advanced stage of disease in EU and CELAC countries participating in this multicentre case-control study based on an “omics integrative epidemiology” conceptual model as a strategy to be extended worldwide.

Our role

ECPC leads WP5 (Communication and dissemination) where our role is to follow the plan for exploitation and dissemination of the results in order to promote the knowledge and advances originating from project.

Our activities in 2022

- ✓ ECPC led updates of project web page, social media and provided newsletters.
- ✓ ECPC cooperated on complex data analysis and translation to clinical practice via participating on online training courses and informing policy stakeholders about the outcomes of the project.

<https://legacy-h2020.eu/>

10. Instand-NGS4P - Integrated and standardized NGS workflows for Personalised Therapy



Consortium includes 7 partners from 5 countries, with a total budget of 10 M €.

Personalized medicine depends on the availability of molecular tests to determine an appropriate diagnosis and select the appropriate therapy. Unlike in research program practices, the application of next-generation sequencing (NGS) in routine in vitro medical diagnostics has a number of additional requirements. Although some platforms suitable for use as an in vitro diagnostic (IVD) medical device already exist on the market and are approved for use in medical diagnostics, whether and how NGS testing could be converted to IVD in a few years' time is under discussion. INSTAND-NGS4P project focuses on improving cancer patient's benefit from Next Generation Sequencing (NGS) by developing an integrated and standardized NGS workflow. For this, it will compile information from cancer gene testing, pharmacogenetics testing and e-medication in proper presentation to medical doctors for supporting therapy decision making at bedside widely applicable in health systems. The project will define unmet medical and technical needs based on an Open Market Consultation, which lays the foundation for a call for tenders addressing solution providers (companies) to develop their products to better meet user needs. Companies responding to this call will be evaluated regarding their ability to answer these users' needs from design perspective until the product phase.

Our role

ECPC participates in WP5 (Stakeholders' engagement, communication, dissemination, education & training and exploitation of project results) gathering and providing the summary of the patients' needs and engagement.

Our activities in 2022

- ✓ ECPC has been essential part of the Patient Needs Consensus Board, contributing to include patient needs in the evaluation of tenders that are going to participate in the study.
- ✓ ECPC participated in the monitoring of patient requirements and information during the study.
- ✓ ECPC ensured the ethical management of privacy and security of patients' data.
- ✓ ECPC contributed to the publication of a consortium paper introducing a section including patient needs in personalised medicine and NGS.

<https://www.instandngs4p.eu/>

11. INTERVENE - International consortium for integrative genomics prediction



Consortium includes 17 partners from 10 countries, with a total budget of 10 M €.

People suffering from complex or rare diseases do not receive adequate treatments due to our inability to effectively prevent and treat many of these diseases, which has a great impact not only for patients but also for their families, physicians, insurers and society as a whole. Although biobanks and medical repositories currently store a wealth of different types of genomic and health data, we do not currently have the appropriate interoperability and standardization tools to exploit them. Analyzing health data in an integrative way, including genetics, -omics and medical records, would be a major breakthrough in disease prediction and personalized medicine. The aim of the INTERVENE project is to develop and test next generation tools for disease prevention, diagnosis and personalised treatment by utilizing the first US-European pool of genomic and health data. If successful, the potential for prediction, diagnosis and personalised treatments for complex and rare diseases will be unprecedented. This project will demonstrate the potential and benefits of powerful AI technologies on the next generation of integrative genetic scores (IGS).

Our role

ECPC participates in WP5 (AI solutions in clinical setting) to assess the participants' attitudes toward genetic information; WP6 (Ethical and legal framework for AI and genetics) to evaluate the trustworthiness, societal impact, and acceptance of AI-based tools; WP7 (Project management and coordination) to ensure effective operation of the project as well as timely delivery of high-quality results and WP8 (Dissemination, exploitation and sustainability of the project outcomes) to ensure sustainability of the outcomes of the INTERVENE project.

ECPC is involved in the ethical and legal framework that will be developed for Artificial Intelligence (AI) and genetics making sure that the patient voices are being represented and incorporated. We are responsible for patient involvement and also serves as a strong partner in communication and dissemination of the project and its results.

Our activities in 2022

- ✓ ECPC reported and disseminated the PhD meeting in Berlin.
- ✓ ECPC co-organised the annual meeting in Helsinki.
- ✓ ECPC helped in the definition of a sustainability plan.
- ✓ ECPC participated in the consortium management group that regulates the functioning and decision making implemented in the different WPs in the project.
- ✓ ECPC attended and helped in the elaboration of the ethical requirements to be implemented in the study.

<https://www.interveneproject.eu/>

12. QUALITOP - Monitoring multidimensional aspects of QUALity of Life after cancer ImmunoTherapy - an Open smart digital Platform for personalized prevention and patient management



Consortium includes 14 partners from 9 countries, with a total budget of 5 M €.

Cancer immunotherapy has brought significant progress in cancer treatment and has resulted in high efficacy for some cancers (e.g., melanoma and acute lymphoblastic leukemia). However, some challenges need to be overcome in order to improve cancer patients' health status and quality of life (QoL) after immunotherapy initiation. On the one hand, there is a crucial need for identifying "predictive markers" of occurrence of immunotherapy-related adverse events to predict and improve patients' health status and promote their QoL. On the other hand, there is a lack of knowledge on patients' health status after the start of immunotherapy outside randomized controlled trials. QUALITOP aims to cover these needs by developing a European immunotherapy-specific open Smart Digital Platform and using big data analysis, artificial intelligence, and simulation modelling approaches. This will enable collecting and aggregating efficiently real-world data to monitor health status and QoL of cancer patients given immunotherapy. Using machine learning approaches, QUALITOP will provide "real-time" recommendations stemming from patient profiles and feedbacks via the Smart Digital Platform. Furthermore, an increased visibility on patients' behavior, a better immunotherapy related adverse events prediction, and an improvement of care coordination will help analyzing through simulation modelling approaches the gain in cost-effectiveness.

Our role

The ECPC is responsible for WP8 Communication/outreach, dissemination, exploitation. We support and collaborate with all the partners to ensure information flow to enable information to be shared. Its main objective is the widest possible dissemination of the project's results to both the cancer patient and research community and all other identified stakeholders.

Our activities in 2022

- ✓ ECPC organized the second online dissemination workshop. The main objective was to discuss about quality of Life of melanoma patients receiving immunotherapy, about the role of social psychology of health and to generate room for further discussion.
- ✓ ECPC provided QUALITOP Newsletter with specialized project interview with Susana Puig Prof. MD PhD, Chief Dermatology Service Hospital Clinic, University of Barcelona.
- ✓ ECPC cooperated on scientific and project coordination activities by preparing the agenda, inviting participants, preparing presentations and, finally, including the recommendation in the reports by providing feedback to the review comments on a project meeting.

✓ ECPC actively participated on a virtual meeting and a face-to-face meeting in Barcelona, Spain, and in Brussels, Belgium.

<https://h2020qualitop.liris.cnrs.fr/>

13. TIGER - Proof of Principle of the best-in-class therapeutic mRNA cancer vaccine



Consortium includes 8 partners from 3 countries, with a total budget of 6.9 M €.

Human Papilloma Virus (HPV) is responsible for over 70% of HPV induced cancers, including cervical cancer and many squamous cancers of the head and neck. The new class of mRNA-therapeutics have the potential to revolutionise care for patients with hard-to-treat cancers and severe unmet clinical needs, but currently none have reached the market. TIGER builds on the current revolution in mRNA-based technologies that offer for a novel best-in-class therapeutic mRNA cancer vaccine platform optimized for intravenous (IV) administration, with the aim to show clinical benefit. The project encompasses essential elements for preparing therapy validation in later stage clinical studies, while addressing patient needs, values and choices.

Our role

ECPC cooperates predominantly in WP5 - Communication, Dissemination and Exploitation

Our activities in 2022

- ✓ ECPC participated in the implementation of the communication, dissemination and exploitation plan
- ✓ ECPC supported communication towards public and promoted the project and its goals through its network
- ✓ ECPC attended regular meetings to ensure exploitation of project's result

<https://tiger-h2020.eu/>

14. OPTIMA - Optimal treatment for patients with solid tumors in Europe through Artificial Intelligence



Consortium includes 29 partners from 14 countries, with a total budget of 10.5 M €.

Continuing advances in the understanding of the complex biology of cancer have driven the development of high-resolution diagnostic technologies, numerous innovative cancer therapeutic agents, as well as generating extensive knowledge on the influence

of a wide range of factors on treatment outcomes. However, these advances are also accompanied by a myriad of challenges we must build on the huge potential of the large volumes of continuously updated real-world data. OPTIMA is a multi-stakeholder-led consortium with the vision that each and every patient should have access to the most up-to-date individualised treatments and to innovative therapies. Following the experience with the predecessor (PIONEER) project, OPTIMA intends to extend its goals to other two cancers, breast and lung cancer. Taking PIONEER as a template and starting point, the idea of this project is to improve the integration of all the information available from patients, translate it into a standardised format, and process it through Artificial Intelligence to achieve the best ways for early diagnosis, personalised therapy.

Our role

ECPC participates in WP2 (Informed consent, general requirement analysis, governance and regulation) to ensure an ethical and legal supporting framework that contributes to sharing data compliant to GDPR and building trust in AI solutions; in WP3 (Guideline-based decision support tool) to identify the relevant guidelines for prostate, breast and lung cancer and will translate these guidelines into decision support tools and WP8 (Dissemination and communication) to ensure broad communication and dissemination of the OPTIMA results and make them available to all the relevant stakeholders

Our activities in 2022

- ✓ ECPC reviewed informed consent forms, surveys, study protocols and guidelines.
- ✓ ECPC set up patient focus groups.
- ✓ ECPC drafted patient information leaflets and brochures
- ✓ ECPC communicated and disseminated project's deliverables.
- ✓ ECPC contributed to the delineation and elaboration of improved guidelines that can reinforced the following of the recommendations by clinicians and patients.

<https://www.optima-oncology.eu/>

15. AIDAVA - AI powered Data Curation & Publishing Virtual Assistant



Consortium includes 14 partners from 9 countries, with a total budget of 7.7 M €.

High-quality, integrated personal health data represent a potential source of knowledge for healthcare systems. However, there is no reliable conduit to make these data accessible and efficiently used by institutions, at national and EU level. AIDAVA's goal is to fill this gap by creating an AI-based virtual assistant that maximizes the automation of the collection and publication of heterogeneous structured and unstructured data. AIDAVA will decrease the workload of clinical data stewards, improve the effectiveness of clinical care and support clinical

research and has the potential to democratise participation in data curation and publishing by citizens/patients leading to overall savings in health care costs and supporting delivery of the European Health Data Space.

Our role

ECPC participates in WP1 (Use cases - Patient Registries; Individual Health records) to involve & support patients during evaluation of the project; in WP4 (Data management) to ensure DMP and processing of data align with internal practice; WP6 (Innovation Management: Communication, Dissemination, Exploitation and Sustainability) to contribute to communication & Networking) and WP7 (Project Management and Scientific coordination) where ECPC contributes to the management and scientific coordination of the consortium.

Our activities in 2022

- ✓ ECPC attended the Kick-off meeting in Maastricht.
- ✓ ECPC participated in the recruitment and follow up of patients' use cases, providing four cancer patients that have started to work as advisors for the development of the project.

<https://www.aidava.eu/>

16. CGI-Clinics: Data-driven cancer genome interpretation for personalized cancer treatment



Consortium includes 18 partners from 5 countries, with a total budget of 9 M €.

The difficulties involved in interpreting tumor genomic data restrict the use of next-generation sequencing (NGS) in clinical cancer management. In addition, it relies on the work of experts reviewing scattered databases and resources in a time-consuming process that can lead to suboptimal clinical decisions. CGI-Clinics aims at improving personalized medicine in oncology by optimizing genomic data interpretation (after sequencing and before advising on compatible targeted therapies). The project addresses the three main obstacles in the interpretation of cancer mutations: the lack of systematicity, the large number of variants of unknown significance and the ineffectiveness of patient empowerment. CGI-Clinics will improve personalized medicine in oncology facilitating the understanding of the information gained through interpretation of their tumors, informed discussions with clinicians and data sharing for research. The project will systematize the interpretation process by integrating relevant public and private databases hospitals in a one-stop shop tool, with the possibility to organize virtual molecular tumor boards co-facilitated by reference hospitals. In addition, it will build eduCGI, an app to help patients to understand the information gained through

interpretation of their tumors, facilitating informed discussions with clinicians and sharing their data for research.

Our role

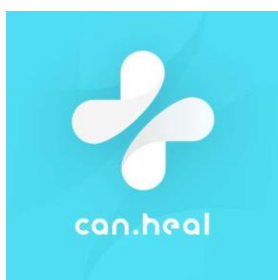
Our organization is leading the Patient empowerment and policies part of the project. It consists of patient empowerment in the use of CGI, the organization of focus groups with cancer patients, caregivers and cancer patient stakeholders to record the patient's perspective, creation of Patient Advisory Board (with 5-8 patients to validate during the need towards the CGI software), patient feedbacks, patient feedback assessment and finally in a result the patient empowerment guidelines and policy recommendations.

Our activities in 2022

✓ ECPC participated in the kickoff meeting which took place in Barcelona on November 21- 23, 2022.

<https://www.cgiclinics.eu/>

17. Can.Heal – Building the EU Cancer and Public Health Genomics platform



Consortium includes 42 partners from 17 countries, with a total budget of 6 M €.

Cancer is strongly driven by genomic modifications, and wide profiling of these modifications with new technological approaches has become a major asset for (early) diagnosis, prognosis and therapy in regard to personalised medicine. The

Can.Heal consortium recognises that prevention, diagnosis and treatment should be approached in a concerted way for optimal benefit of patients and citizens. In particular, the project aims to implement next-generation sequencing technology to identify genetic profiles of patients and tumor cells in a way that can be shared and interpreted across EU cancer centers, leading to improved equity in cancer treatment. In addition, Can.Heal plans to develop cancer risk estimation strategies in healthy populations, establish remote genetic counseling and integrate genomic profiling into paediatric cancer screening, as well as incorporate the Genome Europe biobanking initiative into public health genomics for cancer.

Our role

✓ ECPC co-leads WP2, entitled "Communication, Dissemination and Outreach", with the main tasks of promoting a framework for integrating Next Generation Sequencing (NGS) and Public Health Genomics (PHG) into health systems. This will ensure early diagnosis in conjunction with the other two pillars of the project (Cancer Diagnosis and Treatment for All and Genomics for Public Health) as well as facilitating effective external communication and dissemination of key messages and results.

✓ ECPC's mission is to ensure the central role of patients in this project and their involvement in cancer research and policy-making.

Our activities in 2022

- ✓ ECPC participated in the pre-kickoff online meeting on October 10, 2022.
- ✓ ECPC participated in the kickoff meeting, which took place in Brussels on November 24-25, 2022. During the meeting, ECPC presented the activities of WP2 'Communication, dissemination, and outreach' on the project in collaboration with the European Alliance for Personalised Medicine (EAPM).

<https://canheal.eu/>

d. Treatments

18. Immune-Image - Immune-Image: Specific Imaging of Immune Cell Dynamics Using Novel Tracer Strategies



Consortium includes 22 partners from 9 countries, with a total budget of 15 M €.

Immunotherapies have emerged as effective treatments for immune system-related diseases, such as cancer and inflammatory diseases. However, there is an

unmet need for developing personalized immunotherapeutic approaches since not all patients benefit from them and side effects vary greatly. Although blood and tissue biomarkers have so far played a modest role in assessing immune status in vivo, non-invasive whole-body imaging will make a significant contribution in the future. Immune-Image will develop methods to visualize and study the immune cells involved before, during, and after such treatments allowing selection of the right treatment for the right patient and at the right time. The information obtained about the immune cells and their activity during disease could be used to develop new drugs that might help those patients for which current immunotherapies are ineffective.

Our role

ECPC cooperates in WP1 (Management, coordination, dissemination and sustainability) with all partners to ensure that the Immune-Image project implements and fulfils all the requirements and obligations of the Grant Agreement (GA) and the Consortium Agreements (CA) and in WP2 (Data storage and analysis enablement) in the development of legal and ethical procedures and templates for the data infrastructure and biobanking.

Our activities in 2022

- ✓ ECPC participated in the communication and dissemination group.
- ✓ ECPC collaborated in the organisation of the annual meeting of the consortium.
- ✓ ECPC contributed in the design of the sustainability and exploitation plan.
- ✓ ECPC co- designed and co-organized a questionnaire to survey the opinion and knowledge of cancer patients about the subjects considered in the Immune-Image consortium (Imaging and immunotherapy monitoring during diagnosis and therapy).

<https://www.immune-image.eu/>

19. ImmunoSABR - Clinical proof of concept through a randomised phase II study: a combination of immunotherapy and stereotactic ablative radiotherapy as a curative treatment for limited metastatic lung cancer



Consortium includes 17 partners from 8 countries, with a total budget of 8 M €.

Non-small cell lung cancer (NSCLC) comprises 85% of all lung cancer cases. The majority of patients are diagnosed at the time of metastatic disease, when treatment options are limited and 5-year survival rates are drastically reduced. These patients nearly always develop multidrug resistance to many forms of chemotherapy and targeted agents or immunotherapy work only in a fraction of patients. These patients mainly rely on palliative treatment with a combination of systemic cytotoxic chemotherapy, hormonal deprivation and/or targeted agents. Current treatment strategies result in a median progression-free survival (PFS) of only 2-12 months. ImmunoSABR is geared towards opening up a new paradigm in treating metastatic cancer by obtaining clinical proof of concept for a novel bi-modal curative treatment strategy. The project combines high precision stereotactic ablative radiotherapy (SABR) with immunotherapy to form a powerful synergistic anti-tumor strategy and will gather evidence for the clinical efficacy of this bi-modal treatment strategy in a multicentre randomised phase II study (clinicaltrials.gov no. NCT02735850) in patients with limited metastatic NSCLC. The approach relies on the direct cytotoxic effect of SABR, the abscopal effect of radiation observed at distance from the irradiated metastatic site(s), and the effect of the tumour-specific immunocytokine.

Our activities in 2022

ECPC is a part of the management, dissemination and exploitation of the project and supported the communications through its network.

<https://www.immunosabr.org/>

e. Patients and caregivers

20. DIAdIC - Evaluation of Dyadic Psychoeducational Interventions for People with Advanced Cancer and their Informal Caregivers (DIAdIC): An international randomized controlled trial



Consortium includes 11 partners from 8 countries, with a total budget of 4 M €.

Advanced cancer affects millions of Europeans each year. The provision of adequate and cost-effective psychosocial and educational support for both patients and their frequently overburdened family caregivers is highly relevant from an economic, a healthcare and a prevention perspective. The DIAdIC project is an interdisciplinary, cross-national project to evaluate the effectiveness and cost-effectiveness of two psycho-educational dyadic interventions that target the patient and family caregiver together: a web-based health intervention and a nurse-led face-to-face intervention. Both will be suitable for implementation across diverse healthcare systems. In addition, the project aims are to assess the interventions' effects on vulnerable subgroups (e.g. people with a lower socioeconomic position), their effectiveness in different healthcare systems, and their suitability as perceived by end-users.

Our role

We are responsible for leading the Work package 10 – Dissemination and communication part of the project.

Our activities in 2022

- ✓ ECPC implemented the Dissemination, Exploitation and Communication Plan (external communication activities via website and social media DIAdIC accounts).
- ✓ ECPC participated on regular DEC and Consortium meetings.
- ✓ ECPC reported and disseminated the PhD meeting in Dublin.

<https://diadic.eu/>

21. PREFER - Patient Preferences in Benefit-Risk Assessments during the Drug Life Cycle



Consortium includes 31 partners from 9 countries, with a total budget of 6 M €.

The patient perspective is important in all medical research and particularly in drug development. While industry, regulatory authorities, health technology assessment bodies, reimbursement agencies and patient

organisations all agree that patient preferences are very valuable, there is little guidance on conducting and using such studies. The PREFER project aims to assess when and how patient preferences on benefits and risks should be incorporated into decisions on medicinal products. The goal of PREFER will be to provide a set of systematic methodologies and recommendations to assess, engage and include patient perspectives during the development, approval, and post-approval of new therapies. The project gives an indication of how patient preference studies can provide valuable information to support decision-making and establishing recommendations to support the development of guidelines for industry, regulatory authorities and HTA bodies on how and when to include patient perspectives on the benefits and risks of medicinal products.

Our role

ECPC is actively involved in Work Package 1 – Project management overall management of the project, WP 2 – Patient preference elicitation issues and approaches, WP 3 – Case studies and WP 4 – Recommendation. From the perspective of our main focus on patients, WP numbers 2 and 4 were the most significant.

Our activities in 2022

- ✓ ECPC participated in the final meeting (online) that closed the consortium.
- ✓ ECPC contributed in a paper on the results on patient preferences obtained during the development of the project.

<https://www.imi-prefer.eu/>

22. Lifechamps - A Collective Intelligence Platform to Support Cancer Champions



Consortium includes 15 partners from 9 countries, with a total budget of 5 M €.

The steady increase in life expectancy, mean age and cancer survivorship across the developed countries together with evidence from cancer and geriatrics care research bring forward the urgent need to deal with the “age issue” as a key component of global cancer care strategies. Additionally, increasing age and comorbidities are often associated with a discriminant lower use of aggressive cancer therapies, as well as a higher neglect for their preferences in health-related quality of life care support. Lifechamps aims to address the inherent complexity caused by cancer treatments and to act in the monitoring of health status and improvement of quality of life in a significant manner by using emerging technologies in the fields of Big Data, Data Analytics and Artificial Intelligence. Its Artificial Intelligence (AI) and analytics engine can determine accurately which factors affect the oncological patients during and after their treatment. Furthermore, complemented by a health recommender system LifeChamps offers personalized healthcare services to these patients and their caregivers.

Our role

We are actively involved in activities focused on connection with stakeholders. This means primarily liaison and interaction with several cancer treatment related stakeholders from industry, patients, healthcare professionals and policy makers at EU and country level. Our involvement is a part of Dissemination, Communication and Exploitation of Results.

Our activities in 2022

- ✓ ECPC supported the organization of the 4th Meeting of Minds. It was the first open to the public engagement event of the cluster around the single key question “How can new technologies better support patients?”. ECPC coordinated a round table with cancer patients & patient association representatives and ECPC Past President Kathi Apostolidis gave a keynote speech on the role of patients in R&I and particularly on their motivation to participate in patient-centred clinical and other research initiatives.
- ✓ ECPC co-organized a session entitled Stakeholders Engagement in the European Oncology Living Labs during the ECPC Annual Conference entitled: “The Cancer Policy & Research Landscape in the meta-Covid Era” which took place in Brussels Belgium on the 27th May 2022. The session was attended by cancer patients around Europe and several stakeholders and policy makers.
- ✓ ECPC disseminated Lifechamps project material and the manifesto of the oncology living labs during the 7th ENSP - European Conference on Tobacco Control which took place in Heraklion Crete Greece.
- ✓ ECPC signed Memorandum of Understanding with StandICT s part of the standardization efforts we.eu.
- ✓ ECPC begun collaborating in the area of liaison and interaction with external experts.
- ✓ ECPC conducted two online focus groups with cancer survivors to gather feedback on the mobile application before its official launch. A total of eight participants were invited to test the English version of the app on their own devices and provide feedback through one-on-one interviews with facilitators. The focus groups allowed participants to explore the app at their own pace and provide their opinions on the interface and educational content.
- ✓ During the SIOG Conference 2022 (28-30 October, Geneva), ECPC supported the organization of the LifeChamps project Satelite Event “Integrating digital health technologies in cancer care – opportunities, threats, barriers and facilitators”. The event was aimed at presenting the project’s progress, technologies and results in an international framework. The event was moderated by ECPC Senior EU Affairs Manager Adela Maghear. Charis Girvalaki, ECPC Executive Director, was among the invited speakers and pointed out the barriers that older cancer patients face when adopting digital healthcare technology.

<https://lifechamps.eu/>

23. MyPath - Developing and implementing innovative Patient-Centred Care Pathways for cancer patients



Consortium includes 15 partners from 7 countries, with a total budget of 4.77 M €.

Access to patient-centered cancer care consisting of optimal supportive, palliative, survivorship and end-of-life care is becoming increasingly important as cancer cure rates are rising and more patients are living longer with cancer. However, to date, technical support appropriate to different cultures, settings, and environments is not available. MyPath develops technology-enhanced and evidence-based patient-centred care pathways to be merged with tumour-centred treatments across supportive, palliative, survivorship and end-of-life care. MyPath can significantly improve the quality of and access to treatment and care, reduce variations in clinical practice, and optimise resources in family, community, and hospital care settings. This will ultimately reduce the physical, emotional, and ultimately economic burden linked to cancer.

Our role

ECPC is a part of the work package WP6 – Outreach – Dissemination, exploitation and public engagement. The main goal is to raise awareness and share results of the whole project. We are also leaders of patient engagement to ensure the active involvement of patients in the project including the implementation of patient-oriented lectures, focus groups and a digital forum.

Our activities in 2022

- ✓ ECPC participated in the kick-off meeting held in Oslo.
- ✓ ECPC started to work on the first tasks involving the beginning of the project: arrangements to celebrate a Launch event at the EU parliament to advertise the project.
- ✓ ECPC advised and supported the design and creation of a Patients Board.

<https://mypath-cancercare.eu/>

24. PREFERABLE-II - Personalised Live – Personalised Exercise-Oncology for improvement of supportive care: a super umbrella trial to demonstrate the (cost)effectiveness of live-remote exercise in cancer survivors



Consortium includes 12 partners from 6 countries, with a total budget of 6 M €.

Cancer survivors may suffer from long-term side effects that can lower their quality of life, functioning, and productivity. Exercise interventions have proven to be uniquely beneficial in managing both physical and

psychological complaints. However, their effects are strongest when tailored to a patient's specific burden and their use is limited due to a lack of availability and accessibility and low awareness. To tackle these hurdles, the PREFERABLE-II consortium sets out to design and demonstrate the (cost-)effectiveness of a novel exercise intervention that will be tailored to survivors' side effects, implemented at home, available to all cancer survivors, and incorporated with improved patient-centred communication and shared decision making. Overall, PREFERABLE-II will contribute to improving the quality of life of cancer survivors by lowering the burden of side effects, while also improving availability, access and awareness of exercise-based supportive care interventions.

Our role

ECPC is responsible for Work package 8 – Dissemination, exploitation and communication (DEC). The upcoming tasks for the ECPC will concern the establishment of a Dissemination, Exploitation and Communication Plan for the whole duration of the project and also the preparation, organization and implementation of the Launch event in the European Parliament.

Our activities in 2022

- ✓ ECPC participated in the kick-off meeting held in Utrecht.
- ✓ ECPC participated in the set-up and execution of a tele-system, LION-RCT that may guide and facilitate personalized sports programs for patient survivors.
- ✓ ECPC collaborated in the design of surveys for patients and the arrangements to form Patient Focus groups.

<https://www.preferable2.eu/>

25. RELEVIMUM - Improving quality of life of advanced pancreatic cancer patients through an AI-guided multimodal intervention, combining pain and cachexia management, nutrition, and physical activity



Consortium includes 18 partners from 8 countries, with a total budget of 6 M €.

Pancreatic cancer has the lowest survival rate amongst other cancers and is responsible for 95,000 deaths every year in the EU. Its treatment is usually palliative, aiming at slowing tumour progression and at symptom management. RELEVIMUM hypothesizes that quality of life of advanced pancreatic cancer patients can be significantly improved by reducing pain and cachexia through highly personalised nutrition, physical activity, and pain management strategies, in addition to chemotherapy treatment. To achieve this, RELEVIMUM will empower patients with digital tools that facilitate patient-doctor communication and enable them to self-manage their disease such as a multi-sensor smartwatch and an innovative remote ultrasound patch, AI algorithms for continuous remote monitoring of pain and sarcopenia, and patient and caregiver applications. Combined, these tools will provide a stream of evidence on

symptom progression and will enable physicians to apply personalised care plans. RELEVIMUM brings together an interdisciplinary team of experts and will also involve patients and their caregivers in an iterative co-creation process. The study outcomes will result in recommendations for integrating remote monitoring and improving quality of life outcomes in palliative care for advanced pancreatic cancer.

Our role

Our main participation will consist of bringing together the network of patients, caregivers and policy stakeholders, to be utilized in the co-creation process adopted within for defining the user needs. We will also create a network of national patient organizations in the area of pancreatic cancer. Project will distil the knowledge and experiences acquired during the feasibility and multi-centre studies, along with previous knowledge, to produce a set of recommendations. RELEVIMUM plans to actively involve patient advocacy groups patients, their families and professional caregivers in the design and development of the planned intervention and the associated study protocols.

Our activities in 2022

✓ ECPC participated at the Kick-off Meeting which took a place in Mainz (Germany) where we presented our role within the project and discussed first steps.

<https://www.releviumproject.eu/>

5. Capacity Building

Education & Capacity building activities aimed at providing Members with the tools to advocate for policy change at national level, with new instruments to help people with cancer, and with educational projects to designed to educate people with cancer and patient organizations about issues that are important to them. Capacity building is an ongoing process aiming to support our members in [strengthening their role as equal players in their regional and national healthcare environment](#).

- **The European Cancer Patient Coalition Annual Congress – May 2022**

The European Cancer Patient Coalition's Annual Conference in May 2022 was the first after in person event after the pandemic.

The Annual Conference was in hybrid format and took place in Brussels on 27-28 May, when the European Cancer Patient Coalition welcomed approximately 100 participants. The event gathered a large number of cancer patient organisations in Europe, with participants from 69 ECPC members, from 28 countries. The satellite event that ECPC co-organised with the partners of the LifeChamps EU project, entitled "The Cancer Policy & Research Landscape in the meta-Covid Era", provided an important opportunity for face-to face discussions between cancer patients, researchers, industry representatives and other health stakeholders.

The aim of the Annual Congress 2022 was to offer ECPC members a conference programme highlighting some of the key areas of the emblematic initiatives of the European Commission – the EU Cancer Plan and the Cancer Mission. Our members had the opportunity to hear about the latest developments in cancer policy and research and bring back home information on how the European cancer landscape is changing and how EU Member States could improve their National Cancer Plans.

The ECPC annual Congress 2022 started with a video welcome note from the EU Commissioner on Health and Food Safety Stella Kyriakides and included presentations on the Mission on Cancer, the objective and flagship initiatives of the EU Beating Cancer Plan, the importance of establishing an EU Cancer Survivorship Day in Europe and about what patients should know about sharing data, knowledge and expertise across borders.

The Congress was a great time to meet and reconnect among the ECPC members after two years and a half since the last event took place. ECPC members were invited to the discussions to expand their network, present their work and ideas to others and share their experiences with the COVID-19 pandemic and how it affected them and their organisations.

- **Newsletter**

The European Cancer Patient Coalition's newsletter is distributed to more than 1000 relevant health stakeholders and European cancer patient organisations, that subscribed to the ECPC newsletter database.

ECPC undertakes surveys periodically to monitor the interest of its members in the fields of EU national policy and cancer research, which consolidates our understanding of their needs.

ECPC also provides its members and stakeholders with relevant information on cancer policy and advocacy at the European level. The main objective is to raise awareness among its member organisations on the complex European public health policy landscape. Like this, ECPC's members can understand better the policies that can impact their health and encourage them to proactively contribute to our policy and patient engagement work.

At the same time, the European Cancer Patient Coalition's newsletter summarises the organisation's projects news and initiatives or represent calls for patients' involvement in such research projects as co-creators of their own health.

6. Communication & Awareness

Communication and awareness raising activities including campaigns to empower our Members, cancer patients, and the public.

→ Calendar of main activities in 2022

- Is access to quality biomarker and NGS testing available to European cancer patients? - November 2022
- Cancer and Depression workshop – patient and carer perspectives – October/November 2022
- UICC CONGRESS OCTOBER 18-20 October 2022, Geneva, Switzerland (AS) - ECPC session on Precision Oncology and Biomarkers: opening new therapeutic avenues for cancer patients
- Published the ECPC Patient Guide on Cancer Biomarkers November 2022
- Translated the ECPC biosimilars e-module to Polish
- ecancer and ECPC launched a new platform to help patients navigating genetic and genomic testing - Brussels, Belgium – 25th May 2022

7. Alliances and Partnerships

Strategic Alliances with other organizations, including European institutions, scientific societies and academia that increase the Coalition's capacity to serve the needs of its Members. ECPC counts on the direct, experienced and voluntary support of the Board and Members in the development and implementation of all activities of the Action Plan.

ECPC is a member of the BBMRI-ERIC Stakeholder Forum represented by Kathi Apostolidis, ECPC Past President-Chair Scientific Committee.

ECPC is among the eligible organizations of the EMA and the last ten years is represented by Kathi Apostolidis.

ECPC President, Francesco de Lorenzo is a member of the Board of Directors of the EACS-European Academy of Cancer Sciences.





European Cancer
Patient Coalition



Avenue des Arts 6
1210 Brussels
Belgium
info@ecpc.org
www.ecpc.org