European Cancer
Patient Coalition

Action Plan 2023

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Introduction

Message from the President

Dear ECPC Members, Partners, Sponsors and friends,

2023 will be a landmark year for the European Cancer Patient Coalition, as it will mark its first twenty years of standing by cancer patients, carers and families, across Europe and beyond, and bringing their voice at the highest level in the European Commission, the European Parliament and other EU institutions.

The mission of ECPC that is our beacon, first published in September 2013, clearly states what we stand for today:

ECPC works for a Europe of equality, where all European cancer patients have timely and affordable access to the best diagnosis, treatment and care available and where rare cancer patients have the possibility to seek diagnosis and treatment in a specialized cancer centre in another EU Member State, using the possibilities offered by the ERNs-European Reference Networks and Cross-Border Healthcare Directive.

At ECPC, we work to ensure that the entire cancer care pathway effectively includes prevention, treatment, rehabilitation, survivorship, palliative and end-of-life care.

ECPC derives its mandate to speak with "one voice" for all Europeans with cancer, their carers and families, from its wide membership, covering all cancers, common and rare, and its democratic governance and structure. The President and the Board of ECPC together with the Scientific Committee and the ECPC Secretariat will work closely with all ECPC members, in every EU Member State. Special emphasis will be given on rare cancers, through our Working Group on Rare Cancers, and our participation in the ERN-EURACAN - European Reference Network on solid cancers. For adequately representing the views of European cancer patients and survivors in the European healthcare debate but also on the national healthcare debates, we will continue to enable and empower our members by updating them about the latest developments in cancer diagnosis, treatment, care, rehabilitation, and survivorship and by providing them with the necessary advocacy skills.

The ECPC had on May 28, 2022, its Annual General Meeting, which gave to the new ECPC Board a strong mandate to continue representing the European cancer patients. The ECPC annual accounts, annual reports, and action plans for financial years 2020 and 2021 were voted with a strong majority. The Audit Reports, prepared by external registered auditors for both 2020 and 2021 are positive for ECPC and conclude that without prejudice to certain formal aspects of minor importance, the ECPC accounting records are maintained in accordance with the legal and regulatory requirements applicable in Belgium.

The Action Plan 2023 presented at the Extraordinary Annual General Meeting of July 20, 2022 for voting covers the key pillars of our activities, that are cancer

policy and research together with capacity building of our members. The ECPC plays an essential role in cancer policy in Europe by effectively acting as the voice of cancer patients. The organization is committed to representing patients' interests and proposing patient-centric solutions to cancer-related problems. As such, the ECPC has been a critical stakeholder in defining cancer policy in Europe through its participation in all EU Joint Actions till now. The ECPC has been raising awareness of the key issues that lead to disparities in cancer care; it has also been making practical recommendations to bridge the gap between cancer policy and cancer care practice, as it recently did for access to cancer biomarkers on which precision oncology is based or for recognition of exposure to UV radiation of workers in open air as a cause of skin cancer. Supported by the ECPC capacity building strategy, its +470 member patient organizations have the vital role of advocating for cancer policy recommendations at the national level.

The primary missions of the ECPC are to educate patients, increase their involvement in research and to disseminate information about cancer and cancer research results to the general public. This active engagement of patients is vital to improving the quality of health care in Europe and to understanding patient preferences about their treatment and care, as they are crucial elements of patient-centred care. The research projects allow the ECPC to be at the forefront of scientific developments, and the organization is actively involved in the design and implementation of several EU-funded projects (Chapter 3 Pag.38-54). Within these projects, the ECPC emphasises the importance of involving patients as core researchers and strongly advocates for patients' early participation in defining research priorities and patient-centric treatment decisions.

Among the subjects covered by the research projects in which ECPC participates are the socio-economic disparities in cancer in the European Union, cancer survivorship, precision oncology, genomics, eHealth, novel biomarkers, HTA, Big Data and Artificial Intelligence. ECPC's cancer policy and research activities will be scientifically supported by our recently appointed Scientific Committee, whose members are

1. Prof. Mark Lawler - Associate Pro-Vice-Chancellor and Professor of Digital Health-Faculty of Medicine, Health and Life Sciences - Chair in Translational Cancer Genomics - Patrick G Johnston Centre for Cancer Research -Queen's University Belfast

2. Prof. Francoise Meunier – Vice President of the FEAM - Federation of the European Academies of Medicine - Fellow and Member of the Science Policy Committee of EACS-European Academy of Cancer Science -

3. Ass. Prof. Nicola Normanno - President, International Quality Network for Pathology (IQN Path) and President, Italian Cancer Society (SIC)

4. Prof. Ulrik Ringborg - Director - Cancer Center Karolinska - Karolinska University Hospital Solna

5. Dr. Kostas Stamatopoulos - Hematologist – Director INAB/CERTH Institute of Applied Biosciences-Greece - Coordinator of the National Network of Precision Oncology (2018-2022) - Visiting Professor-Karolinska Institute

The Scientific Committee will support the Board of Directors in planning and foresight of cancer policy and research, and it will be chaired, as foreseen by ECPC Statute, by Kathi Apostolidis, as ECPC Past President and Chair of the Scientific Committee. The Scientific Committee members welcomed their appointment stating that:

"We recognise the need for a strong European patient advocacy organisation, representing the views and needs of patients across Europe, particularly with the additional challenges that the Covid-19 pandemic and the war in Ukraine are presenting and will continue to present for cancer care, for cancer research and most of all for cancer patients in Europe. We are impressed by the scope of research projects that ECPC are involved in and look forward to hearing in more detail about these projects and providing our expertise to help in your aspirations in patient-centred cancer research.

We see that ECPC has a key partnering role with many organisations around Europe, particularly with the emergence of a number of initiatives relating to both the European Beating Cancer Plan and the EU Cancer Mission. It is critically important that ECPC is deeply involved in actions relating to projects, programmes and policies that intersect with both these cancer specific initiatives and we hope that our knowledge and expertise can help guide ECPC in their efforts to help support cancer research and cancer policy that delivers for the benefits of patients. Additionally, ECPC showed real leadership in helping to establish the Cross Parliamentary Party Cancer Intergroup, an initiative that we trust will grow and have influence in the corridors of power of the European Parliament."

It should be noted that 2023 will be a year during which most of the flagship actions and projects of both the EU Cancer Plan and of the EU Cancer Mission will be proclaimed. ECPC will not stop advocating for best cancer diagnosis, treatment and care, before these planned actions and projects of the EU Cancer Plan are implemented in every EU member state.

I am deeply honoured and consider it a great privilege and personal challenge to be entrusted by our members with their votes and be re-elected President of this great organization for a third mandate, as ECPC reaches its first 20 years of life. On this occasion, I would like also to welcome the 27 cancer patient organizations that became members of the ECPC in 2021 and in the first semester 2022.

ECPC's persistent efforts during the last nine years have positioned cancer more prominently on the European political agenda and have yielded results, from policy to capacity building to research. We will continue with your support to represent in Brussels all cancer patients from all EU member states.

"Nothing about us, without us"

Francesco De Lorenzo

ECPC President

Meet the ECPC team

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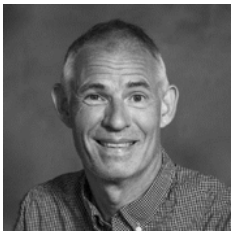

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The European Cancer Patient Coalition's 2022 key areas of involvement

In 2022 and 2021, the challenges of 2020 continued for both the cancer community worldwide and ECPC. The COVID-19 pandemic continued to spread around the planet, sending billions of people into lockdown, as health services struggled to cope. As this disease can endanger cancer patients directly or indirectly, ECPC has been strongly committed to provide its members and the larger cancer community with the most updated information also on the vaccines to ensure that cancer patients are safe and protected during the pandemic.

The coronavirus pandemic has severely disrupted cancer care, revealed weaknesses of health systems, and it will have a significant impact on new cancer diagnosis in the following years. This situation has led ECPC to prove its resilience, adaptability and commitment to its mission: a Europe of equality, where all European cancer patients have timely and affordable access to the best treatment and care available, throughout their life. For that reason and, to ensure that the rights of cancer patients are respected, ECPC will organize a webinar at the beginning of 2023 to better explain what our role is in each research project.

Francesco de Lorenzo, the President of ECPC, has been more than ever committed to promote patients' centred role. Among ECPC achievements and worth mentioning developments in 2021-2022 that will affect cancer policy and research in 2023 and beyond are the following:

1. The Expert Conference on Oncology by the Czech Presidency

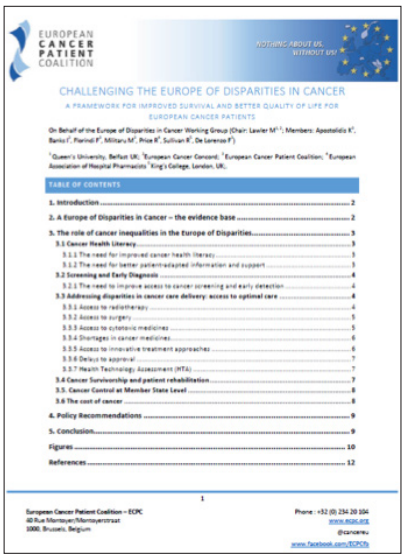
On July 13-14, the ECPC President, Francesco de Lorenzo was invited to represent ECPC at the Expert Conference on Oncology *"Modern Cancer Control: Saving Lives through Smart Solutions"* in Brno, Czech Republic, organized by the Czech Presidency of the Council of the European Union.

On this occasion, the ECPC President emphasized that cancer patient organizations should request to be involved in the process of establishing the Comprehensive Cancer Infrastructures (CCIs) at EU level. This rightful request for involvement will be in implementation of the recommendations and goals of the Europe's Beating Cancer Plan and of the EU Cancer Mission. The request stems from the importance of patients' involvement in cancer research activities as well as of having patients at the centre of the digital transformation of health.

During the discussion with the Czech Health Minister Vlastimil Válek, the Czech Deputy Minister of Health Jakub Dvoracek and the European Commission Team Leader of the Cancer Taskforce Matthias Schuppe, Francesco De Lorenzo also stressed the need to introduce diagnostic tests for early detection of lung and prostate cancers as part of the national screening programmes and taking care thatpatient preferences should be considered in the planning and establishment of the CCI network to be achieved by 2025.

3. The HTA Regulation

Access to new and innovative medicines and treatments remains one of the most significant inequalities across Europe. Cancer patients currently face the paradox of life-saving new medicines and treatments becoming available in Europe, yet not accessible to them, depending on which Member State they reside.


EUROPEAN CANCER PATIENT COALITION

NOTHING ABOUT US WITHOUT US!

CHALLENGING THE EUROPE OF DISPARITIES IN CANCER

A FRAMEWORK FOR IMPROVED SURVIVAL AND BETTER QUALITY OF LIFE FOR EUROPEAN CANCER PATIENTS

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ECPC highlighted the severity of delays in the 2015 report **"Challenging the Europe of Disparities in Cancer"**, where it was demonstrated that access to life-saving cancer medicines was delayed for years mainly due to differences in ricing & Reimbursement methodologies and HTA evaluations. The existing approach of parallel assessments by HTA bodies in every EU Member State, using different methodologies represents a wasteful duplication of effort and time. In the EU, there are more than 50 national and regional HTA bodies, all embedded in different institutional settings.

ECPC is proud to have created momentum on the European Union cooperation on HTA during the process of amending the regulation 726/2004, voted by the European Parliament in 2016. A call for the European Commission to develop a proposal for EU cooperation on HTA followed.

In January 2018, the European Commission set out a proposal for a regulation for future EU cooperation on HTA. The proposal focuses on the joint work on clinical aspects of HTA, which are typically based on global evidence, while the non-clinical aspects remain at Member State level. In early 2019, ECPC launched an online educational module for cancer patients on HTA, which helped to increase knowledge and confidence of ECPC members to participate in HTA bodies at national level, and advocate for it, where there are no established frameworks for patient involvement in HTA. Within 2020, ECPC developed a toolkit for patients and patient organizations on how cancer patients can be involved in the HTA process.

The HTA regulation has been adopted at the end of 2021. The challenge though remains in the implementation as described in Section 2.1. ECPC will continue to closely monitor the progress in 2023 and to bring its added value as a relevant stakeholder in the policy debate at the EU level.

4. Cancer research

As research falls under the competence of the European Commission, but healthcare is a national competence, bio-medical research could serve as a catalyst between research and healthcare, thus, strengthening the social impact of translational research in cancer, integrating the patients' perspective.

ECPC acts as the missing link between all the relevant stakeholders, always keeping in mind patient centricity, ethics and sustainability. ECPC emphasises the importance of involving patients as co-researchers, very early when planning the research questions and strongly advocates for a partnership model between researchers and patients, allowing patients to contribute their unique experience, working towards a more patient-centric study, while participating in crucial project decisions. The main objective in 2023 on health and research is to drive results and achievements from the European research projects that are meaningful to patients, having ECPC as the connector between the scientific world and the European cancer patients. Our organisation is an active partner in studies that generatenew technologies such as genetics, artificial intelligence, digital health tools and data management, to improve treatments and care of cancer patients. With this purpose in mind, since patient-centred cancer research is to become the standard in Europe in the long term, ECPC will continue to engage with the oncology community and European Institutions on the principle of **"Science with and for Society"**, becoming even more closely aligned to the needs of patients.

Our work on European Union funded projects continued in 2022, including ***26 Horizon 2020 (H2020) projects, 2*** Innovative Medicine Initiative (IMI) projects, while numerous new project proposals were submitted. The main areas covered are: personalised medicine and genomics, the use of artificial intelligence in prevention and therapy improvements, digital health, rare cancers, palliative care, nutrition in cancer.

ECPC's contribution to cancer research and care has been further recognised by having ECPC representatives invited to Boards and Committees of top-level European cancer organisations, such as European Academy of Cancer Sciences-EACS, Cancer Drug Development Forum – CDDF, WIN Consortium, BBMRI-ERIC, Pancreatic Cancer Europe-PCE, All.Can and EU Health Coalition.

5. Personalized Medicine – Biomarkers

Following on its first survey in 2016, through which ECPC attempted to understand how much its members knew about biomarkers and their role in cancer diagnosis, prognosis and treatment, ECPC pursued its efforts for capacity building of its members through sessions on personalized medicine, biomarkers and liquid biopsy in its Annual Congresses, patient guide, papers and the specific awareness campaign in November as Personalized Medicine Month.

In 2020, ECPC in collaboration with IQNPath and EFPIA worked on an initiative to "improve cancer care through broader access to quality biomarker testing". The goal of this initiative is to identify barriers to biomarker testing in EU27 and the UK and to develop policy recommendations in order to ensure that all eligible cancer patients have access to the ideal testing paradigm: high-quality biomarker testing that is readily available to all cancer patients without compromising on the numbers of genes analysed, with new tests rapidly integrated into the standard of care. ECPC succeeded to convince the survey partners about the need to elicit to

the level of European cancer patients' knowledge about biomarkers, the level of information about biomarkers relevant to their cancer shared by their physicians, and their own experience with novel biomarker testing.

Despite the difficulties imposed by the covid-19 pandemic to run the survey, it was successful, since despite the delays the survey was completed in October 2020 and its results were presented in February 2021 at an event at the European Parliament. The continued pandemic in 2020 and 2021 delayed the live dissemination of the findings of the survey in as many countries as planned. However, country round tables, press conferences, presentations at congresses and conferences, publication of papers in medical journals and of country survey reports have already taken place in 2021 in a number of the countries participating in the survey, namely, Italy, Greece, Spain, UK, while a few more were planned in 2022.

In 2023, the partners plan to organize a few more country round tables, publish papers on the results of the survey and an Advocacy Guide for cancer patient organizations, based on the findings of the survey, as well as infographic tables explaining the uses of the most used biomarkers and giving more information on liquid biopsy.

6. The "Challenge Cancer" Parliamentary Intergroup

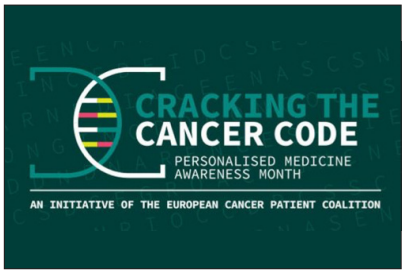
CHALLENGE CANCER
EU PARLIAMENTARY INTERGROUP

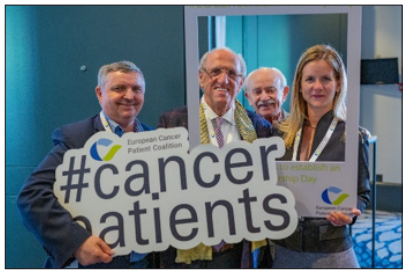
The Intergroup has strengthened its presence and action, and several events were organised and endorsed with the support of ECPC, which is managing the secretariat of the Intergroup. The main topics covered during 2022: survivorship care, rare cancers, cancer research, personalised medicine, the implementation of the EU Beating Cancer Plan.

ECPC, as the voice of cancer patients in Europe, has taken a prominent role in the dialogue with the European institutions and will continue to engage with the oncology community for implementation of the Cancer Mission and the Europe's Beating Cancer Plan.

7. Awareness campaigns

ECPC collaborated closely with its Members across Europe on several awareness raising campaigns, such as **'Cracking the cancer code'** campaign on personalised medicine, **'20 million reasons to establish an EU Cancer Survivorship Day'**, and the **'Make Sense Campaign'** on head and neck cancers. ECPC's fundamental role is to be the voice of its members in Europe and to represent them within European institutions. Each one of ECPC Members' is essential for the work of the organisation.





1. The European Cancer Patient Coalition Activities

The main objectives of the 2023 Action Plan are to further support and advocate for cancer patient rights, to develop a strong engagement with the European Institutions members, to strengthen and make more frequent the connection with ECPC members, partners, and stakeholders during a period of many challenges in both the internal and external environment.

1.1 Policy and Advocacy

ECPC's added value and main mission is to represent the voice of people affected with cancer in Europe. To do so, ECPC will continue to follow and contribute to a variety of health policy issues at the European level, based on our Action Plan and Strategy and to follow and intervene in, where appropriate, on the main EU health, research, and other relevant policy topics. In 2023, the European Cancer Patient Coalition will focus on developing several policy themes as described in Section 2.

1.1.1 Pharmaceutical Strategy

ECPC will be strongly involved in the Pharmaceutical Strategy for Europe, as reported in the Europe's Beating Cancer Plan specifically following the reform of the basic pharmaceutical legislation, which will propose ways to improve access to medicinal products, including to generic and biosimilar medicines. The Strategy also started initiatives to secure supply chains and respond to shortages of medicines, It will also seek to boost innovation to address the unmet needs of patients, while making sure treatments remain affordable.

The EU Beating Cancer Plan stresses the need for all cancer patients to have access to innovative medicines and therapies. This aspect has been further developed within the HTA Regulation. The Plan also mentions that the revision of the Orphan and Paediatric Regulations will look to improve the conditions for authorising new cancer medicines for use in children. In line with these, ECPC will work closely with the Members of the Challenge Cancer Intergroup and the upcoming Swedish and Spanish Presidencies at the Council, to ensure that the future legislative proposal (expected in the Q4 of 2022) will propose measures to foster innovation and address the unmet medical need in the area of rare cancers, while ensuring a faster approval process for such medicines.

1.1.2 Cancer Patients survivorship

By the end of 2022, the European Commission will launch the 'Cancer Survivor Smart-Card', an ambitious flagship initiative described by the EU Beating Cancer Plan and aimed at including the clinical history, follow-up care and cancer survivors' real-life experiences in a portable eCard or app. The Card is also

expected to improve communication and coordination between patients and their health professionals.

In this sense, ECPC signed a Memorandum of Understanding with the Organisation of the European Cancer Institutes (OECI) to establish a model to include survivorship care in the national cancer plans and to develop multidisciplinary national centres for cancer survivors. ECPC will also participate in several EU Funded projects aiming to improve survivorship of cancer patients either through mobilizing and building capacity in individuals and organisations to create, adapt and explore purposeful use of interoperable digital health solutions based on a shared adoption of the European Electronic Health Records Exchange format across Europe or contributing in projects which are designing, developing, piloting and delivering the web IT tool of the prototype (mock-up) version of the 'Cancer Survivor Smart Card and the criteria of the specific tool.

1.2 **Health and Research**

ECPC in the period 2022-23 will participate in 21 Health and Research projects (10 ongoing H2020 and 11 New Horizon Europe starting in 2022), and 5 new proposals, where ECPC is acting to implement the Patients interests into the design, the experimental mechanisms, and the goals of the studies. These research projects cover all stages in the cancer patient's course and have as the main aim the improvement of the patient's quality of life.

Implementation of programs and tools for cancer prevention are a priority. Reducing new cases or monitoring high risk groups will benefit potential patients and health care systems. ECPC is partner of studies using new approaches on prevention, such as the EU H2020 project INTERVENE. This project intends to use large genetic analysis and artificial intelligence to spot high risk individuals allowing taking preventive measures or early diagnostics, resulting in better prognosis in case that the establishment of the disease cannot be avoided.

New trends in cancer therapy consider individual patients, using specific biomarkers to determine early diagnosis and personalised therapies. Personalised medicine has greatly improved the way that patients face cancer treatments, with the use of new molecular-directed and immune-promoting drugs. An EU H2020 project, INSTAND-NGS4P, aims to implement the use of genetic sequencing as a standard tool to be used around Europe to facilitate the analysis of genetic markers that will allow a more defined diagnosis and more efficient design of the therapeutical approach. We are major partners in this study: leading a patients' board involved in the selection process of external companies that will provide the materials to develop the experimental procedures of the study. ECPC will also contribute to the development of a manuscript that will cover the application of the genetic sequencing to the personalisation of the therapy for individual patients. Genetic sequencing clinical application results in the optimisation of what is so called pharmacogenetics. This consist in targeting therapy that includes drugs design to specifically recognise and be active for specific DNA mutations or recognising specific molecules present in the tumor. ECPC will make sure that most known genetic mutations and tumor

markers are part of the study, covering as many groups of cancer patients and possible. We will also push for the inclusion and investigation of new markers and mutations that may be applied to current cancers not yet covered by this technique and the addition to rare and childhood specific cancer types.

We are also active in projects intending a wider use and efficacy of Immunotherapy to reach a larger population of patients that can benefit from this new treatment that has proven to be effective in many previously hard to treat cancers. As partners of the EU H2020 project IMMUNE-IMAGE, we are trying to increase the accessibility of Immunotherapy to European cancer patients. This study tries to define an individualised patient approach, using a combination of imaging techniques, to determine the best diagnose and therapy for the individual patient based on the detection of cellular and molecular markers. ECPC has a leading role in the design and dissemination of a survey that will allow the consortium to learn about the needs and gaps that may help to modulate and improve the scope of the project. ECPC is also a major contributor to the sustainability plan, defining the patient-oriented goal of the follow-up implementation of the study's achievements after the end of the project, promoting full access for all European patients.

We are also partners of projects such as OPTIMA, which aims to use artificial intelligence (AI) to integrate clinical and molecular data from patients all around Europe to improve the efficacy and side-effects of cancer therapies. ECPC is contributing to the delineation of recommendations and guidelines for health care givers and patients that will help in the decision-making process, ensuring the active participation of the patient. We will participate in the analysis of the results, considering the patient's needs and quality of life are prioritised.

In the course of the patient's disease, life after treatment is in many cases a major concern for the person. Improve the quality of life of cancer survivors is also a priority of the EU cancer programmes. ECPC is partner in several EU projects focused on the care and amelioration of the consequences of the, sometimes severe, treatments. A project studying the use of Palliative Care in different parts of the EU (PALLIATIVE SEDATION), tries to prepare guidelines that could homogenize and improve the use of sedatives in the terminal stages of some cancer patients. We are contributing to the recruitment of patients and the designing of educational programmes that can adequately inform patients, families and caregivers about the solutions and support available and the adjustment to different social, moral and religious environments.

A new, and long proposed, research area in the EU cancer plans is the use of digital tools that can help patients to deal with their diseases, manage and decide how to use their clinical and molecular data. We are supporting and participating in the designing and writing of new EU proposals. ECPC participates in a proposal, COCANSMART, which aims to develop and implement a European e-smart cart that would allow patients to access and share their clinical data in any part or health care system of the EU.

Besides EU projects, ECPC is leading or promoting other research projects, covering rare cancers, digital health, nutrition and comorbidities. We collaborated with investigators from Milan (Italy) and Jean (Germany), in the design and analysis of a survey focused on the importance that Nutrition has during the course of the disease for a cancer patient. This is the continuation of

a previous survey that allowed us to prepare a guideline to help patients to get awareness about the proper nutrition to improve their quality of life. Now, we expect to advance in the awareness with an improve campaign that may cover the gaps and needs not targeted in the previous survey. We are also working on a manuscript that will analyse and show the consequences that the COVID-19 pandemic has had for cancer patients and the different impact between west and eastern European countries.

1.3 **Education & Capacity Building**

The European Cancer Patient Coalition is there to serve its Members. Building the capacity of ECPC Members improves the capability of patient organisations to develop, implement, and advocate at the national, regional, and global level throughout continuous education, initiatives and programmes.

ECPC is as strong as the bond between the organisation and its Membership. During the last years ECPC membership almost doubled. In 2022 Conference and General Assembly, ECPC renewed its contacts with old and new members, after almost 2,5 years of COVID-19 restrictions. To maintain a strong trust with our members, we provide quality services to better respond to the needs of cancer patients' organisations on the field. For this reason, in 2023, ECPC will invest time and resources to increase and potentiate educational and capacity building initiatives towards its members and empower them to advocate at country level also through sharing best practices.

The 2023 education and capacity building objectives are to increase and continue the dialogue between the Coalition and its Members to ensure increased capacity for both.

1.4 **Communication and Awareness Raising**

In 2023, ECPC will continue the work on communication and awareness raising campaigns.

The updates on the website started in 2022, we will continue working on improvements, daily maintenance and implementation with new features as we develop new projects.

Awareness campaigns of the previous years will continue in 2023, while new ones will be added. Throughout 2022we have also supported campaigns of our partners and members, and we will continue to do so throughout 2023 (Section 5).

1.5 **Strategic Alliances**

In the last decade, ECPC established and consolidated its relationship with several other non-governmental organisations and European Academic and

Research Institutions, such as the European Society for Medical Oncology (ESMO), the European Academy of Cancer Sciences, All.Can Intl, Pancreatic Cancer Europe (PCE), WPCC World Pancreatic Cancer Coalition, the Cancer Drug Development Forum (CDDF), European Alliance for Personalised Medicine (EAPM), Worldwide innovative networking in personalised cancer medicine (WIN), The European Nutrition for Health Alliance, Federation of European Academies of Medicine (FEAM), Union for International Cancer Control (UICC), European Organisation for Research and Treatment of Cancer (EORTC), European Association of Urology (EAU), European Medicines Agency (EMA), European Cancer Organisation (ECO), the EU4Health CSO contributing to a compelling pack of joint initiatives.

In relation to strategic alliances, the objective for 2023 is to keep building upon the established partnerships in order to expand them in new areas serving the needs of ECPC members and to, possibly, enhance new partnerships relevant to the implementation of ECPC's Strategy.

2. Policy and Advocacy

2.1 Health Technology Assessment-(HTA)

Duration: June 2023 – December 2023

Context

The long-awaited HTA Regulation was finally adopted at the end of 2021. This regulation is well-timed to end the confusion and misinterpretation on the actual clinical impact and added value of innovative medicines. The regulation can positively impact the treatment outcomes of cancer patients while reducing inequalities to innovative therapies.

During the recent years, ECPC has been actively involved to ensure that both the objectives and the implementation of this regulation will address disparities, reduce barriers to accessing innovative treatment, recognise the true value of new therapies, and improve the sustainability of national healthcare systems.

The challenge remains in its implementation, namely how to manage the 3-year transition period until the Regulation applies, from January 2025, towards a feasible system so that the objectives of the Regulation can be achieved. To overcome this, there is a need for shared responsibility between EC, Member States, HTA agencies, patient representatives and industry. Only if all relevant stakeholders work together during the next coming years, we can build a system that is future-proof and is able to deliver high quality outputs that are relevant for decision making in Member States.

Such collaboration should consider the advances in the regulatory pathways to better reflect the specificities of a disease and the ambitions of the EU Pharmaceutical Strategy. In this way, it can ensure that both current and future patients can benefit from innovative therapies in a timely manner.

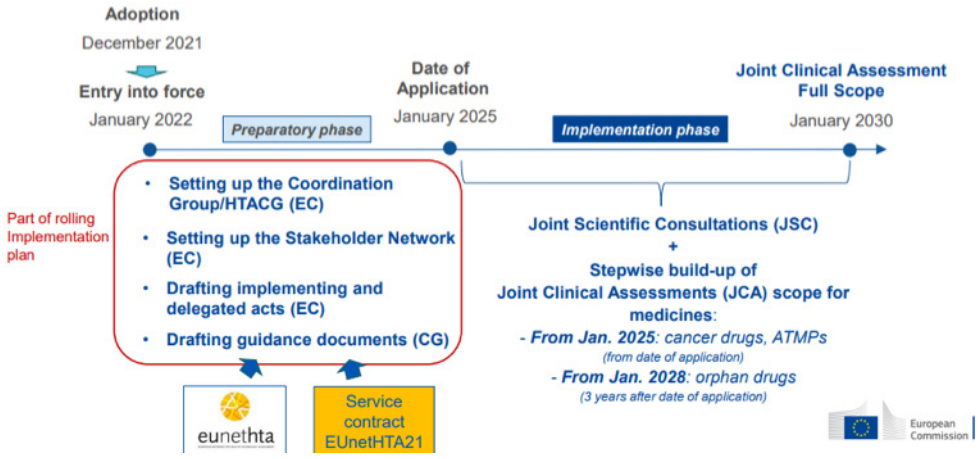


Figure 1. HTA Regulation – Implementation timeline (Source: European Commission)

As described in the above figure, the first joint clinical assessments at the EU level within the HTA Regulation coming into force in January 2025 will be achieved for cancer drugs. ECPC is very pleased to see that our recommendations of about a decade ago will finally become reality.

The HTA Regulation is important for cancer patients because it allows governments to adopt cancer care services that are more efficient and of a higher quality, while also considering the effect of cancer on quality of life and its cost burden to patients and health systems.

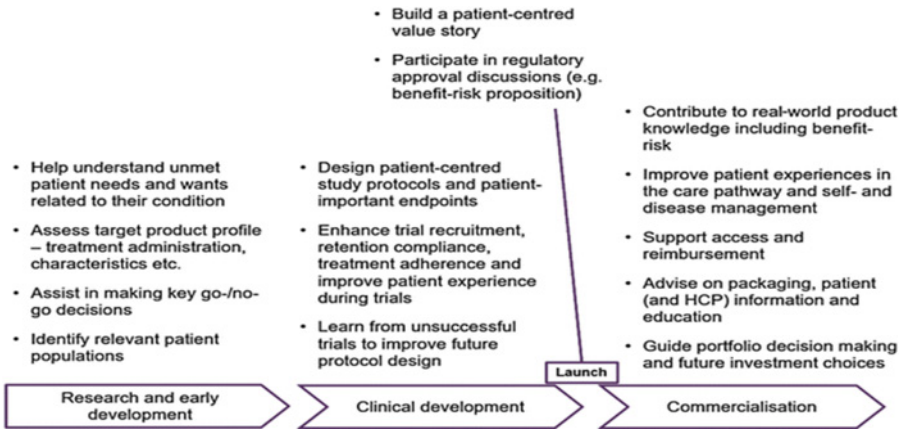


Figure 2. Making Patient Engagement a Reality - doi: 10.1007/s40271-017-0264-6. 2018 Feb;11(1):1-8

Mandatory cooperation and uptake of Joint Clinical Assessment (JCA) reports is the best approach for successful cooperation in this field, in order to provide equal and timely access to valuable cancer therapies. However, cancer patient organisations have a key role at the national level to advocate for harmonised reimbursement schemes to ensure that the new therapies are also affordable for patients. This will be reached by being directly involved, through the Member State Pricing and Reimbursement Agency, in the Health Technology Evaluation process, concerning issues such us Quality of Life, social, ethical and legal aspects.

In addition to this, through its close work with the Challenge Cancer Intergroup and the Czech Presidency, ECPC will initiate a discussion in the Council of Ministers about how to harmonize the reimbursement schemes in the EU Members States to facilitate the access to innovative medicines for all cancer patients.

Objectives

As Member States continue their efforts to recover from the COVID-19 pandemic there is an immediate need for stronger, enabled and empowered patient organisations at a national level.

ECPC strives to enable and empower member organisations to urge national policymakers to protect cancer patients' right to participate in HTA bodies and advocate for a formalised framework of patient involvement in the EU HTA, at national and regional levels. ECPC aims to equip patient organisations at national level to be ready to participate in HTA bodies and provide meaningful contributions on non-clinical aspects, such as quality of life, legal and ethical aspects associated with medicines and treatments, thus allowing to inform their real value at national level.

ECPC aims at equipping its members by:

- Continuing to raise awareness of the importance to be involved in the HTA process through the further dissemination of the HTA e-module and toolkit, its translation in several European languages and the implementation of HTA workshops in person or remotely
- Empowering its members to advocate for their active involvement in the HTA process in their country
- Informing policy makers at EU and national level on the effectiveness of involving patients and their representatives in the HTA process

Actions

- Conduct research and update the toolkit with more information on additional countries
- Prepare a hub of info material that we can use freely for our members
- Prepare infographics to increase awareness around HTA
- Translate and adapt the toolkit in at least 2 EU countries and languages and add country specific information. The decision will be made by releasing a call for interest to our members.
- Raise awareness and build on the HTA workshops. One at European level involving all the relevant stakeholders and 2 additional in selected EU countries. ECPC will organise online workshops for patient organisations to increase the visibility of the toolkit.
- ECPC will organize HTA trainings to activate member patient organisations, to prepare them with more detailed guidance on patient involvement and seek input from members in countries where patient involvement in HTA is more advanced.
- Training for HTA Experts

Deliverables

- Updated and tailored version of the toolkit for two additional countries
- Hub of information for patients and patients organizations
- Translations of the toolkit
- 2 EU wide in partnership with ECPC Members
- Training sessions for ECPC Members with detailed information on patient involvement in HTA bodies.

Timeframe

- Month 1-6: Update, adaptation and translation of the toolkit
- Month 1-9: Preparation of the hub

- Month 1-6: Organisation of the Workshops
- Month 10-10:2Organization of HTA trainings for activate member patient organisations

2.2 Personalised Medicine

Duration: January 2023 – December 2023

Context

Each year, over 3 million people are diagnosed with cancer in Europe. During recent years, personalised medicine has gained importance in cancer prevention, diagnosis, prognosis and therapy. It is now steadily introduced into daily clinical practice of healthcare professionals, including various individualised, molecularly targeted therapies with increased efficacy and/or reduced toxicity.

Personalised medicine has an important role to early identification of cancer predisposition genes, as a screening procedure may help high risk populations to make important decisions on individual risk-modification behaviours. *In addition, early cancer diagnosis in high-risk individuals significantly increases the chances of complete recovery.* Cancer treatment can also be benefited as there are molecularly distinct subtypes of various common cancers, with different therapeutic approaches required for each subtype.

The proven efficacy of several targeted approaches shows that a new era in the field of oncology is raising and requires decisions based on each person's individual profile and characteristics with the ultimate goal to improve patient prognosis and quality of life.

We need governments to ensure the means to identify people who may benefit from more effective targeted cancer treatment and avoid treatment-related toxicity, where possible, all while helping to ensure the sustainability of our healthcare systems.

One such way to address this is with molecular tumour testing, or biomarker testing, and personalised medicine, a targeted approach to the prevention, diagnosis and treatment of cancer. Awareness about molecular and genetic tumour profiling remains low – only 23% of European doctors feel that their patients are always fully informed about molecular or biomarker testing. Through involvement in the Innovative Partnership on Action Against Cancer (iPAAC), ECPC will also use the contribution of the Joint Action on genomics to further increase awareness. The use of cancer molecular testing in Europe also varies by country, because in many countries diagnostic tests are not integrated into clinical practice and are not reimbursed or available to all people with cancer. *The access to novel diagnostic technologies such as next generation sequencing (NGS) is limited in most of European countries. A recent survey by ECPC, IQN Path and EFPIA revealed that on average less than 10% of biopsies are tested with NGS in Europe, with huge difference between Northern Europe countries versus Southern and Eastern Europe.* This needs to change as it further deepens the inequalities in Europe.

ECPC is in the position to build a vital bridge between all the relevant stakeholders involved ensuring continued dialogue that drives meaningful change.

Objectives

ECPC aims to continue its efforts to put personalised medicine for cancer prevention, diagnosis, prognosis and therapy into the spotlight of the European and national health agenda and will build-up on its Personalised Medicine Awareness Month in November called "Cracking the Cancer Code" with the aim to promote the importance of access to cancer biomarker testing and molecular testing. However, as the use of cancer molecular testing in Europe also varies by country, ECPC will continue to advocate for a common European policy applied to all Member States that will integrate personalised medicine in oncology (genetic profiling, molecular testing) into clinical practice, secure fair reimbursement policies and accessibility to all European citizens who need it.

Actions

In 2023 ECPC will work on the following actions:

- Raising awareness, towards creating a common European consensus and delivering more in-depth yet easy-to-understand patient information
- Using the experience and the outcomes of the joint action (partner in the Innovative Partnership for Action Against Cancer-iPAAC) to support a paradigm shift on the use of genomics
- Disseminating information on the access and quality of biomarker testing in the different European countries using the results of the European survey on biomarkers by IQNPath-ECPC-EFPIA,
- Use the knowledge produced by several EU funded projects of which ECPC is a partner to support and promote the importance of Personalised Medicine
- Engaging with experts and policymakers to drive concrete policy recommendations stemming from policy discussion in the European Parliament
- Support ECPC members wishing to advocate on their national level about approval and reimbursement of cancer biomarkers and NGS

Deliverables:

- Pan-European Awareness Campaign during the Personalised Medicine Awareness Month (November), #ShareYourPersonalStory
- Update the campaign toolkit for ECPC member patient organisations, healthcare professionals and patients to run campaigns at national level
- Update the Personalised Medicine Guide for patients
- Prepare infographics with the latest updates on the role of biomarkers in cancer care including the increasing role of biomarkers and of liquid biopsy for hard to get tumor samples and different role of biomarkers in different cancers

- Dissemination of the booklet and its translation in several EU languages (n. of languages depending on funding available)
- Videos with patients' testimonies and online material for the social media campaign
- *National roundtables to discuss barriers to the access to biomarker testing and propose national/regional plans to improve the clinical implementation of precision medicine*

Timeframe:

- Month 3-11: Planning and organisation of the personalised Medicine awareness campaign
- Month 6-10: Update of the of the Personalised Medicine Guide for patients and translation into several EU languages
- Month 6-10: Preparation infographics with the latest updates on the role of biomarkers in cancer care
- Month 5-10: Preparation of the patient's testimonies videos
- Month 6-12: Organization of at least two roundtables on access to biomarker tests and precision medicines
- Month 10-12: Dissemination of the booklet

2.2.1 Awareness raising on the IVDR Implementation challenges

Context

The In vitro Diagnostics Regulation (IVDR) has been developed to revolutionise the current policy framework related to new therapies and diagnostics. Its 5-year transition period ended in May 2022, however its full implementation still seems to pose challenges for patients, users and manufacturers.

Given that COVID-19 crisis has created such an unprecedented situation where there is a clear need for substantial additional resources, we must increase the availability of vitally important medical devices. These extraordinary circumstances have a significant impact on various aspects covered by the IVDR (EU) 2017/745, such as the designation and work of notified bodies and the placing on the market and making available on the market of medical devices in the EU.

The new IVDR promises to bring important changes for patients who rely on these devices to improve their health and quality of life, and, of course, patients have the fundamental right to expect that these devices are safe, after being authorised for use in the EU. The changes that the new IVDR brings include enhanced safety requirements particularly for high-risk devices, strengthened transparency and strengthened post-market surveillance. In that regard, the

IVDR aims to modernise the current policy framework for in vitro diagnostics across the EU, putting great emphasis on their safety and reliability. It will bring various improvements in terms of oversight of these tests (pre-market and post-market), the level of clinical evidence, as well as their safety and performance, while bringing more transparency for patients and for the public in general.

At the same time, the IVDR is expected to improve clinical relevance and discontinue the use of obsolete diagnostic tests.

In vitro diagnostics, especially companion diagnostics, play an essential role in personalised oncology and the patient-healthcare pathway. In this case, IVDs are not used to treat patients but as non-invasive tests used for diagnosis, screening, assessing predisposition and monitoring.

Personalised medicine is given great consideration within the EU Beating Cancer Plan. In this sense, the plan lists the Cancer Diagnostics and Treatment for All that aims to support greater sharing of tumour profile data with the aim of optimising cancer diagnosis and treatment and reducing inequalities in access to personalised medicine.

While there is a clear need for an updated in vitro diagnostics legislation at the EU level, the IVDR shows some challenges, especially when it comes to its implementation. Despite the encouraging promises that the implementation of the IVDR would, on the one hand, ensure patients' access to new medical technologies and patients' safety, and, on the other hand, give public access to information and fully transparent regulatory framework, the challenges it presents for IVD manufacturers point to a potentially high impact on patients who may lose access to innovative diagnostic assays and technologies. Currently, there is a lack of guidance from authorities on how to follow the new rules in order to certify tests and an insufficient number of notified bodies in place to handle the certifications of future tests.

With this in mind, the European Cancer Patients Coalition would like to raise awareness on the challenges and barriers of the IVDR implementation that could hamper patients' access to new diagnostics.

Objectives

The overarching aim of this project is to raise awareness on the challenges that the IVDR implementation IVDR poses for new cancer diagnostics and to make policy recommendations aimed at ensuring a unified transition to the new regulatory framework, where relevant stakeholders (i.e., healthcare professionals, health institutions, manufacturers and national competent authorities for medical devices) will cooperate efficiently to ensure that cancer patients will continue to benefit from timely access to safe and high-quality medical devices. The activities have been planned to be as streamlined as possible so that policy recommendations are provided in a timely way, to inform the implementation of the IVDR.

Actions

- Developing two surveys, one targeting national and european organisations and the other aimed at in vitro cancer diagnostics manufacturers. These surveys are expected to provide relevant information on the current situation

on how the IVDR has been transposed and implemented at the national level at the end of its 5-year transition period.

- Developing a policy report with recommendations on the implementation of the new IVDR. This policy report will include the state of the art of the implementation of the IVDR at the national level, as resulted from the 2 surveys mentioned above, listing the challenges and policy recommendations to address these.
- Launch event. ECPC will co-host with the members of the Challenge Cancer Parliamentary Intergroup a public event aimed at presenting the policy report to relevant policymakers. Besides the MEPs members of the Challenge Cancer Intergroup, we would invite leading EC figures, patient organisations, manufacturers, national health authorities, health professionals to attend and/or speak. We could also include a panel discussion and consider methods to allow for participant engagement e.g., breakout rooms and live e-polls on key discussion topics, as feasible within the time allowed.
- Communications activities to disseminate our recommendations (October – December) with a strong focus in November (Personalised Medicine month). We will leverage the policy report through a communications campaign organised around the launch event.

Deliverables

- Surveys results report
- Policy report
- Launch event report

Timeframe

- Month 1-6: Surveys preparation and data collection
- Month 6-9: Analysis and launch of the survey's results
- Month 7-10: Policy report
- Month 9-10: Launch event

2.2.2 White Paper on Personalised Medicine

Context

Personalised medicine is given great consideration within Europe's Beating Cancer Plan. In this sense, the plan lists several upcoming promising initiatives that include aspects that clearly recognise the value of personalised medicine, such as:

- Cancer Diagnostics and Treatment for All -to be launched in 2022
- Partnership on Personalised Medicine – to be established in 2023 under Horizon Europe

- New collaborative projects in high performance computing and artificial intelligence to support treatment decisions and advance personalised medicine
- A Cancer Inequalities Registry

Despite the encouraging goals of the EU cancer plan, it is unclear how the proposed initiatives will materialise in practice to improve patients' outcomes. The implementation of such initiatives should not divide Europe from East to West and must reflect lessons learnt from existing work across the region.

Well-known factors like variations in areas such as workforce capacity and quality, reimbursement, data infrastructure and awareness of patients, the public and policymakers lead to unequal access to personalised medicine for the EU citizens.

With this in mind, the European Cancer Patients Coalition would like to pilot the development of a white paper in one of the Member States through the establishment of a multi stakeholder platform. The white paper will highlight key areas for consideration in the development of the Commission's proposed initiatives around personalised medicine..

Aims, objectives and activities

The overarching aim of this project is to develop a white paper consisting of a set of policy recommendations to ensure that the initiatives funded under Europe's Beating Cancer Plan effectively support equal and timely access to personalised medicine in one of the Member States as a pilot.

The Member State to start with the pilot project is to be decided.

Activities

- Developing a multi stakeholder platform of patient associations the country to be selected, health NGOs and other relevant stakeholders that are active in the field of personalised medicine
- Organising 2-3 online meetings to discuss and draft the content of the white paper on personalised medicine that should be structured as follows:
- Literature review – describing the recent developments in the field of personalise therapy, their benefits for patients and factors that impede patients' access to these
- List of gaps identified in the country to be selected that hampers the implementation of personalised therapy
- List of policy recommendations to address the existing gaps
- A call to action to policy makers and relevant stakeholder at both the EU and national level to drive the change in the field
- Follow up – the members of the platform will work together to support the implementation of the policy recommendations and will advocate for a successful call to action initiative.

2.3 CAR-T Treatments

Duration: January 2023 – December 2023

Context

The emergence of cancer therapies that convert chimeric antigen receptor T (CAR T) cells into cancer-fighting cells during the last two years, gave new hope to cancer patients and clinicians. CAR- T treatments were considered as one of the most exciting developments in the endless course to control cancer. CAR-T is an FDA and EMA approved cell therapy for the treatment of certain blood cancers that have not responded or have stopped responding to treatments. The approval was based on a ground-breaking clinical study demonstrating that CAR-T treatment could eradicate blood cancer in patients who had received many unsuccessful rounds of traditional blood cancer therapy. 83% of these patients were in complete remission after only three months of CAR-T treatment.

However, unlike the till now known conventional cancer treatments CAR-T is not a medicine produced in bulk. The delivery of CAR-T cell therapies is complex, since it is not industrially produced as other medicines and treatments, but each treatment must be engineered as new for every patient. The preparatory process starts by blood collection, removal of the patient's T cells, followed by insertion of a gene for a synthetic protein called a chimeric antigen receptor, then reinfusing the processed T cells into the patient to spot and destroy tumours.

CAR-Ts offer enormous promise but also come with important scientific, clinical, logistical, policy and regulatory challenges.

In 2021, we have started establishing a multi-stakeholder collaboration at pan-European level - bringing together patients, industry, CAR-T experts (oncologists, haematologists, cell transplants) and others in order to ensure patient access and realise the full potential of CAR-Ts for patients and identify and discuss challenges and potential policy solutions.

In addition, we conducted a literature review to support the development of a white paper with policy recommendations to help improve the effectiveness of current regulatory frameworks and policies, and to inform the development of future regulation and policies relating to the delivery of CAR-Ts to patients in Europe.

For 2022, the development of patient education material is in progress as well as the rest of the activities foreseen for this year.

Objectives

Cancer patients, policy makers and other relevant stakeholders currently lack the necessary information about CAR-T treatments, starting from understanding what this treatment is exactly, how and where it may be delivered, patient eligibility criteria, benefits and risks of the treatment, remission/cure possibilities, availability and reimbursement in their country, possibilities to be treated in another EU member state using the provisions of the Cross Border Health Care Directive. European cancer patients and policy makers need to know more about the potential of new approaches to cancer treatment.

Moreover, the European health systems need to be prepared for the delivery, pricing and reimbursement of these new treatments. Special centres need to be established for the safe and state of the art selection of eligible patients, delivery of the treatment, patient follow-up, monitoring and treatment of adverse events requiring a high level of expertise of multidisciplinary teams. Another significant obstacle to patient access exists—reimbursement. These new personalised therapies do not exactly fit into existing private health insurance or government/ public insurance fund payment models. The treatments approved come with a very high price tag, to which if the related hospital and home care costs are added, make the treatment inaccessible for most patients.

Actions

ECPC, realizing the importance of these new personalised treatments and the need of patients and families to get trustworthy answers from experts to questions around the CAR T treatments, aims to:

- Further develop the platform of patients and caregivers, clinicians and other healthcare professionals, industry representatives, geneticists, pharma industry, payers and other experts and stakeholders to delineate the access problems from the patient perspective.
- Prepare infographics for patients and caregivers explaining the details of the CAR-T treatment pathway and translate it in selected languages (n. of languages to be defined according to where the therapy is available).
- Produce educational material on the latest developments of the treatment including solid tumors (n. of languages to be defined).
- Prepare educational videos on selected topics such as quality of life after treatment
- Organize a dedicated stakeholder conference co-hosted by the Challenge Cancer Parliamentary Intergroup to debate the benefits and risks of these new CAR T treatments, access barriers, treatment delivery, pricing and reimbursement as well other topics that may emerge, to present policy recommendations for the delivery of and access to these new treatments.
- Organize a peer-to-peer session of patients and caregivers who received CAR-T treatment to record their experiences, perceived barriers and needs during the ECPC Annual Conference.

Deliverables

- Stakeholders Platform
- Infographics for patients and caregivers
- Educational material
- Dedicated 1-day stakeholder conference
- Peer-to-peer session of patients and caregivers

Timeframe

- Month 1–12 Further development of the CAR T Platform and constant increase of outreach and membership
- Month 2-10 Preparation of infographics and educational material
- Month 3-6: Preparation of Peer-to-peer session of patients and caregivers
- Month 6- 10: Dedicated 1-day stakeholder conference

2.4 Cancer-related complications and comorbidities

Duration: June 2023 – December 2023

Context

Cancer-related complications and comorbidities are a highly significant burden on patients across Europe. In many cases fatal, but they are too often neglected when it comes to policy and research. At present, there is a strong momentum in the EU policy landscape to bring attention to this area.

It is time to increase the attention given to cancer patients' long-term wellbeing and quality of life, addressing the often-debilitating comorbidities and complications of cancer, both in terms of the disease itself and its treatments. An increasing population of survivors with needs for long-term follow-up care and management of complications and comorbid conditions will place a substantial burden on health systems, as well as on informal carers who provide essential support to them.

It is crucial that, with this renewed focus on cancer, we take a comprehensive and integrated care approach to ensure better health outcomes and quality of life for all European patients, independent of age, gender and state of treatment.

Objectives

Given the current context, the purpose of this initiative is to increase awareness on the patients needs and help to create momentum for EU action on better integrated care for patients, looking not only at the impact of comorbidities on cancer patients, but also the impact of cancer on other diseases and conditions.

Key objectives include the need for more research funding on cancer-related complications and comorbidities, the need to increase awareness among patients, caregivers, health care professionals and policymakers, and the need to promote increased safety in hospitals.

Structure

The initiative brings together various organisations active or with an interest to do more on cancer-related complications and comorbidities. Member organisations of the initiative increase constantly, as they hear of the initiative or we reach out to them.

The initiative released a joint Statement at the end of 2019 and since then it is constantly updated aiming at making cancer-related complications and comorbidities an EU health priority. The initiative is now endorsed by 31members:

1. European Cancer Patient Coalition (ECPC) - CHAIR
2. Associations Collaborating on Hepatitis to Immunize and Eliminate the Viruses in Europe (ACHIEVE)
3. European Association for the Study of Obesity (EASO)
4. European Association for the Study of the Liver (EASL)
5. European Association of Urology (EAU)
6. European Brain Council (EBC)
7. European Cancer Organization (ECO)
8. Eurocarers
9. European Federation of Neurological Associations (EFNA)
10. European Federation of Nurses (EFN)
11. European Geriatric Medicine Society (EuGMS)
12. European Network for Smoking and Tobacco Prevention (ENSP)
13. European Nutrition for Health Alliance (ENHA)
14. European Pain Federation (EFIC)
15. European Society of Oncology Pharmacy (ESOP)
16. European Society of Surgical Oncology (ESSO)
17. European Society of Cardiology (ESC)
18. European Specialist Nurses Organisation (ESNO)
19. European Thrombosis and Haemostasis Alliance (ETHA)
20. Global Alliance of Mental Illness Advocacy Networks-Europe (GAMIAN-Europe)
21. International Psycho-Oncology Society (IPOS)
22. International Society on Thrombosis and Hemostasis (ISTH)
23. International Society of Geriatric Oncology (SIOG)
24. Thrombosis Ireland
25. Thrombosis UK
26. University KU Leuven (KU)

27. Leuven Cancer Institute (LKI)

28. Obesity Policy Engagement Network (OPEN-EU)

29. The European Federation of the Associations of Dietitians (EFAD)

30. The European Society for Clinical Nutrition and Metabolism (ESPEN)

31. The European Hematology Association (EHA)

ECPC is leading on the initiative and currently providing for the secretariat of the initiative. Dr Anna Falanga member of ETHA is the scientific lead of the initiative. The White Paper on Cancer Comorbidities and Complications aims to further communicate this issue at EU policy level and by individual organizations in their own activities, was also launched during 2021. In addition to this, a summary of the White Paper was produced.

During the European Week Against Cancer, and in the light of the EU Beating Cancer Plan, the ECPC, the Cancer Complications and Comorbidities Initiative Members and the European Parliamentary Intergroup "Challenge Cancer" organised five webinars, taking place from Tuesday 25th to Monday 31st of May 2021. Finally, ECPC with the contribution of the members of the Initiative, prepared and submitted to 22 MEPs who are also BECA committee members, 75 amendments on the BECA Committee draft report proposed by MEP Véronique Trillet-Lenoir on "Strengthening Europe in the fight against cancer - towards a comprehensive and coordinated strategy," 43 of which were proposed by several MEPs to be included in the final version.

2022 activities still in progress, include the publication of a policy paper, the launch of a survey on complications and comorbidities, the production of infographics and the production of a Roadmap for the implementation of the Europe's Beating Cancer Plan.

Actions

- Joint Statement: A Joint Statement by all participating organisations serves to develop a joint call to action and the basis to unite all the members of the initiative. In broad terms, it calls for a move towards integrated care. This document can be used by the endorsing organisations in their own activities and in the discussion with EU policy makers. The document is yearly updated.
- European Week Against Cancer event series: Building on the 2021 success, a series of events (live or online) on Cancer related complications and comorbidities will be organized. Several stakeholders from various sectors, cancer organizations, patients, caregivers and policy makers will be invited to participate.
- The results of the European online survey will be used to design and launch a European Awareness Campaign and toolkit on Cancer Complications and Comorbidities
- Setting up a meeting with the Special Committee on the COVID-19 pandemic: lessons learned and recommendations for the future (also COVI Committee) and advocating for priorities for cancer complications and comorbidities in the EU health policy agenda

- Event at the EU Parliament: An event at the EU Parliament will be organised to present the results of the European survey, sensitize MEPs on the issue and put forward the call to action within the context of the Europe's Beating Cancer Plan implementation phase. It will be co-hosted by the Parliamentary Intergroup Challenge Cancer in Q3 of 2023.

Deliverables

- Strategic plan for the year 2023
- Follow up meetings with relevant stakeholders
- Implementation of Europe's Beating Cancer Plan Roadmap
- Awareness campaign and toolkit
- A high-level meeting at the European Parliament
- Online events on Cancer comorbidities and complications

Timeframe

- Month 1-5: Awareness campaign and toolkit preparation
- Month 1-5: European Week Against Cancer events series preparation
- Month 9-12: Organisation of a high-level meeting at the European Parliament to present the results of the survey.
- Month 9-12 Setting up a meeting with the European Commission to request creating a thematic network on this topic in the EU Health Policy Platform - Agora. ECPC to lead this initiative in collaboration with other partners.

2.5 Challenge Cancer Intergroup

Duration: January 2023 – December 2023

Context

The European Parliament Challenge Cancer Intergroup is the first and only EU Parliamentary Intergroup on cancer. It is chaired by MEP Cristian Bușoi, and co- chaired by MEPs Alessandra Moretti, Ald Patriciello and Frédérique Ries,with the European Cancer Patient Coalition (ECPC) providing its Secretariat.

The Intergroup was conceived by ECPC in 2020 to ensure continuity in the European Parliament's work on cancer during the previous and the current mandates. The Intergroup serves as a forum for MEPs from all political parties to engage in dialogue with patients, cancer survivors, carers, scientific and medical societies, research institutions, think tanks, medical practitioners and researchers, policy makers and leaders of the health industry, civil society at large, national governments, and institutions. It acts as a two-way communication channel by holding hearings and

debates and leading fact-finding missions on salient topics such as prevention, access to treatment, medicine shortages, cancer research on quality of life, innovation in cancer care, and survivorship.

The Intergroup is the result of ECPC ongoing commitment and involvement in supporting the "Mission" concept in Research and Innovation, adopted by the European Commission, together with prominent scientists, physicians and researchers, members of the European Academy of Cancer Sciences (EACS)

Objectives

Based on the abovementioned, ECPC, with its 499 members of cancer patient organisations across the EU, aims to act as the intermediary between the Intergroup and European cancer stakeholders and civil society at large. The close collaboration of ECPC with the members of the Intergroup enables its members to access real testimonies and patient experiences, while allowing citizens to express their needs directly to European policymakers. This collaboration is aimed to provide a valuable contact point for MEPs with an interest in cancer policy to exchange views, best practices and access direct information on how cancer and its care are regulated in their countries.

In its capacity as the Secretariat of the Intergroup, ECPC wishes to work toward providing the members with access to real patient experience and a variety of European and national cancer stakeholders, while allowing citizens to express their needs directly to European policymakers. ECPC will make use of its ability, across its pan-European network of organisations, to share knowledge, to influence public health and cancer policies.

Finally, thanks to the data gathered from various cancer sources, the Intergroup strives to influence the goals and guide the implementation of the Cancer Mission, Europe's Beating Cancer Plan and other European cancer and health related policies.

Actions

In 2023 ECPC will work on the following actions:

- Ensuring the involvement of cancer research, prevention/health care and cancer patient communities at all stages of policymaking
- Discussing with the European Commission and other relevant stakeholders the state of play of the implementation of the EU Beating Cancer Plan at the EU and national level
- Discuss the access to funding opportunities for the implementation of the EU Cancer Plan as foreseen in the EU4Health Programme
- Discussing the cancer patients' challenges in times of pandemics like COVID-19 and the role of policy makers in ensuring a more sustainable health system that will be able to cope with future crisis
- Raising awareness on the challenges that a cancer survivor faces during and after treatment and work with the members of the Intergroup to propose measures to improve the quality of life of cancer survivors during treatment and after (White Paper on Social Disparities, The Right to be Forgotten project)

- Discussing policy measures to address social disparities and inequalities in cancer care across EU Member States. The Cancer Inequalities Registry launched in early 2022 as one of the flagship initiatives of the EU Beating Cancer Plan has started a momentum for the EU to develop policy measures to address disparities and inequalities between Member States and regions. The ECPC White Paper 'Challenging the Europe of Disparities' represents a good source of data to start the policy discussion.

- Advocating on biosimilars and the policy measures needed to make such therapies available at the national level

- Supporting MEPs in the Intergroup to work with patient organisations at national level to ensure the timely and appropriate implementation of the EU Joint Action on Rare Cancers (JARC) recommendations for the Rare Cancer Agenda 2030

- Discuss with the European Commission, upcoming Swedish and Spanish Presidencies at the Council and national authorities the implementation at the national level of the objectives raised by the EU Beating Cancer Plan on rare cancers

- Work with MEPs in the Intergroup to ensure a functional Cross-Border Healthcare Directive that will enable collaboration and coordination between the ERNs and the Comprehensive Cancer Centres (CCCs); discuss means to support patients with rare and ultra-rare cancers to access treatment and reimbursement schemes abroad

- Advocating with MEPs to ensure that cancer-related complications and comorbidities are a central part of all policy discussions about cancer care and that they will be considered an individual pillar in the EU Cancer Plan

- Raising awareness on the importance of preventative measures, such as vaccines, and the importance that patient education plays in eliminating HPV-related cancers in Europe

- Discussing the cross-border challenges and potential policy solutions to ensure patients' access to CAR T cell therapies

- Informing MEPs on the effectiveness of involving patients and their representatives in the HTA process, as key players in the implementation of the HTA Regulation, to ensure that patients' unique expertise and knowledge on certain disease contexts is well reflected in the joint assessments

- Informing MEPs about the importance of the complementary cancer treatments, such as physical activity and nutrition, and their role to propose measures to integrate such treatments in the clinical practice at the national level

- Discussing and proposing solutions on how the EU can use digital innovation to offer cost-effective tools to support the transition from a hospital-based healthcare model to a person-centred and integrated model, improve health promotion, prevention and access to care, and contribute to the sustainability and resilience of healthcare systems, in view of the ongoing legislative process on the European Health Data Space (EHDS)

- Engaging with MEPs and experts to drive concrete policy recommendations stemming from policy discussion within the Challenge Cancer Intergroup

Deliverables:

- 2 informative webinars for MEPs, their assistants and their policy advisors on cancer-related priorities
- 3 internal meetings for the members of the Intergroup where MEPs can debate on the proposed topics and decide on the legislative steps to be taken
- Support Challenge Cancer Intergroup MEP members to incorporate the thematic of the Intergroup in external meetings and events
- Amendments to the ongoing legislative pieces

Timeframe:

- Months 6-12: Members of the Intergroup will be involved and supported in internal and external meetings and events
- Month 5-6: Webinar on the non-melanoma skin cancer and on Cancer Complications and Comorbidities
- Month 6: Webinar on the EU Survivorship Day
- Month 9: Webinar on head and neck cancer
- Month 11: Webinar on personalised medicine

2.6 **Covid19**

Duration: January 2023 – December 2023

Context

The WHO indicates that older people are more vulnerable, particularly when they have underlying health conditions such as chronic lung disease, cardiovascular disease, diabetes, chronic kidney disease and active cancer and the impact of the pandemic is yet to be assessed.

ECPC in an effort to provide information to cancer patients has set up a Web Hub accessible from the home page of the website (https://ecpc.org/covid-19-information/).

The pressing question that cancer patients and survivors face is whether they are at increased risk. ECPC has gathered trustworthy information from WHO, ASCO, ECO and ESMO to inform its members accordingly. The categories of cancer patients at increased risk for #COVID-19 infection are the following:

- Patients having chemotherapy, or who have received chemotherapy in the last 3 months
- Patients receiving extensive radiotherapy

- People who have had bone marrow or stem cell transplants in the last 6 months, or who are still taking immunosuppressive drugs
- People with some types of blood or lymphatic system cancer which damage the immune system, even if they have not needed treatment (for example, chronic leukaemia, lymphoma or myeloma).
- Specific risk groups are cancer patients with an impaired immune system such as:
- Leukocytopenia
- Low immunoglobulin levels
- Long lasting immunosuppression (steroids, antibodies).

Patients are advised to discuss their individual risk profiles, due to the primary haemato-oncological disease and the above-mentioned factors and comorbidities, with their treating oncologist. Cancer patients should follow the instructions of WHO and of their national health authorities. They should consult their physician regarding continuation of their treatment, diagnostic tests, and most importantly if they develop any symptoms.

On 10 March 2022, the European Parliament established a new "Special committee on the COVID-19 pandemic lessons learned and recommendations for the future", set up for a 12-month term. COVI's work will focus on four pandemic-related areas: health; a coordinated response respecting democracy and fundamental rights; the societal and economic impact; and the EU and the world. ECPC will closely follow up with the discussions to ensure the voice of cancer patients' is heard as we aim to recover, reinvent and reinvest in health to build a resilient European Health Union for citizens across Europe.

Objectives

ECPC aims to raise awareness on cancer complications and comorbidities during and after the COVID19 recovery with a focus on quality of life.

Actions

- Meeting with the COVI Committee Chair
- Present the impact of COVID19 pandemic to cancer patients and address their unmet needs
- Launch the result of the 2022 survey to assess the impact of the COVID19 pandemic to assess its impact on cancer patients
- Publish a Joint Letter on the impact of COVID19 pandemic on cancer patients, in collaboration with the "Cancer Complications and Comorbidities initiative" which is led by ECPC
- Create a social media campaign to raise awareness about the impact of the COVID19 pandemic
- Organise a public hearing in the European Parliament during the COVI Committee's debates to advocate for cancer patients.

Deliverables

- Joint Letter with relevant stakeholders on the impact of the COVID19 pandemic to cancer patients
- Public hearing in the European Parliament on the impact of the COVID19 pandemic to cancer patients
- Results of the COVID 19 survey
- Awareness campaign

Timeframe

- Month 1: Meeting with the COVI Committee Chair
- Month 1-6: launch of the Survey on the impact of the COVID19 pandemic to cancer patients results
- Month 6-8: Joint letter on the impact of the COVID19 pandemic to cancer patients, with the support of relevant partners
- Month 9: Submission of the survey results for publication
- Month 9-10: Organise a public hearing in the European Parliament during the COVI Committee's debates on the impact of the COVID19 pandemic to cancer patients

2.7 Non-melanoma skin cancer

Duration: January 2023 – December 2023

Context

Non-melanoma skin cancer (NMSC) refers to all the types of cancer of the skin that are not melanoma. In recent decades, the incidence of NMSC has continuously increased and will continue to do so in Europe and worldwide. NMSC is by far the most common cancer diagnosed in light-skinned people. The role of ultraviolet radiation (UVR) in carcinogenesis has been investigated by scientists and solar radiation has been classified by WHO/IARC as a Group 1 human carcinogen. Indeed, 90% of NMSC can be attributed to excessive exposure to UVR. Outdoor workers are exposed to an UVR dose of at least 2 to 3 times higher than indoor workers. NMSC has a significant impact in reducing patients' quality of life as they potentially undergo repeated rounds of surgery or recurrence and, as a result, can suffer significant consequences for their appearance, self-esteem, and well-being.

Despite being one of the most common occupational diseases in Europe, it is yet to be widely recognized and recorded as such. While the prevalence of the disease is continuously increasing, patients are still left behind by healthcare systems, with prevention efforts, screening and access to treatment and care needing significant improvement.

Hence, it is important to improve the understanding, education, and awareness

of the population on NMSC, and set up measures at European level to promote early screening and detection of skin malignancies as well as to increase awareness and protection but also the access to treatment and quality of life of patients and caregivers.

In 2020, ECPC conducted a literature review and produced two awareness factsheets (one for the general public and one for the policymakers). The material was used to support the social media Campaign organized by ECPC entitled "Facing the Sun."

In addition, on 8th and 12thOctober, the follow-up workshops of the Multi-Stakeholder Summit on Occupational Skin Cancer (OSC) by solar UV radiation (UVR) at the workplace co-organized by ECPC and EADV. The follow-up workshops of the Multi-Stakeholder Summit on OSC provided the optimal opportunity to build consensus around the key necessary steps to improve NMSC and OSC reporting, the needs of the NMSC community and the potential benefits of officially recognizing NMSC as an occupational disease. This effort continued during 2021, with 2 online events.

Objectives

ECPC aims to:

- To inform and empower the general public and outdoor workers on the importance of awareness and protection from UVR
- To raise awareness of the importance of implementing legislative measures to protect EU citizens from developing NMSC and improve treatment and quality of life for patients and caregivers

Actions

ECPC will update the "Facing the Sun" social media campaign. The toolkit will be available for ECPC member organisations to use at national level and translated in selected languages. The new toolkit will be launched during the Skin Cancer Awareness Month.

In addition, ECPC will join forces with relevant organisations to organize a workshop (2 breakout sessions) with several stakeholders and policy makers to reinforce the importance of the implementation of EU legislative measures to protect citizens and especially the high-risk population from UVR. The workshop will also aim to map the gaps and propose policy solutions to improve the quality of life for patients and caregivers.

During the Personalised Medicine Awareness Month, ECPC will launch an online campaign (#ShareYourPersonalStory) and videos with patients' testimonies including patients with NMSC. Finally, ECPC, will organize ad hoc meetings with Members of the EU Parliament and the Challenge Cancer Intergroup.

Deliverables

- Toolkit for social media campaign and infographics

- Report of the workshop/webinar
- Joint letter for amending the CMRD5 Directive: Protecting workers from exposure to carcinogens, reprotoxics and mutagens at work to include UVR

Timeframe

- Month 6: "Facing the Sun" social media campaign implementation
- Month 6: ECPC - EADV joint workshop
- Month 6: Survey on non-melanoma skin cancers
- Month 6: Joint Letter on Non-melanoma skin cancers
- Month 7-11: Patients testimonies videos
- Month 6-12: ad hoc meetings with Members of the EU Parliament and the Challenge Cancer Intergroup

2.8 **Big Data and Digital health**

Duration: January 2023 – December 2023

Context

Our health data are routinely collected when visiting health care facilities. This is to optimize treatments and follow up on health history or on outcomes of treatments. With the world now becoming more and more digital, and the citizens of the world more and more mobile, there is a need to be able to access health data and be in control of when, where and how we want to share them. Unfortunately, often these data are collected with us not being fully aware or these data are used for commercial reasons.

90% of EU citizens agree to access their own health data and 80% of the citizens agree to share their health data if privacy and security are ensured. With the creation of eHealth tools and new technology, the patients will be in charge of their own health data and be able to have it readily available with them wherever they go if ever needed.

In 2021, ECPC brought its contribution to the two stakeholder consultations presented by the European Commission on the establishment of the EU Health Data Space (EHDS). The creation of a European Data Space is high on the 2019-2025 Commission agenda and was said to include the health sector. In 2022, ECPC welcomed the publication by the European Commission of the proposal on a Regulation on a European Health Data Space as a positive step towards a more harmonised, interoperable, safe, and trustworthy environment for health data, but also as a tool to strengthen cooperation, improve cancer research and ensure more equality for patients.

Together with the opportunity to use digital health to improve overall health outcomes of EU citizens there are several challenges linked to maintaining

control of own health data, privacy issues, ethical concerns, etc. To drive the creation of a patient-centred European Health Data Space and at to enhance the positive impact that the EHDS could have on patients and cancer care, ECPC will work closely with relevant MEPs, policymakers and stakeholders to ensure that the new legislative tool will provide a clear framework to improve transparency and trust in health data use and re-use for patients at large.

Objectives

Seeing the impact that the COVID-19 pandemic has had on the screening, diagnosis, treatment, and follow-up of cancer patients, ECPC would like to stress the importance of putting cancer patients and survivors at the core of the digital momentum. Cancer care would benefit from the enabling of the cross-border sharing of real-world health data.

Actions

ECPC will develop a toolkit to promote digital health literacy and its implementation among cancer patients, especially among those from disadvantaged groups (people living in rural areas, elderly). The toolkit will be further disseminated among the large network of members of the organisation.

ECPC will work closely with the relevant MEPs in charge of the EHDS dossier to develop policy recommendations and amendments to the regulation. Also, at the end of the legislative process, ECPC is planning to organise an event in the European Parliament to raise awareness on the benefits that the new act brings for patients and also on implementation challenges that might arise.

Deliverables

- Toolkit for patients on digital health literacy Policy recommendations and amendments sent to the European Parliament on the EHDS Regulation
- EU Parliament event

Timeframe

- Month 1-4: Toolkit for patients design
- Month 1-7: Work with relevant MEPs on policy recommendations and amendments to the EHDS Regulation
- Month 9-10: European Parliament event
- Month 10-12: Discuss the implementation of the EHDS with the members of the Challenge Cancer Intergroup
- Month 5-10: Disseminate the toolkit among ECPC members

2.9 **Cancer and Inequalities**

Duration: January 2023 – December 2023

Context

In 2018, ECPC worked with the European Organisation for Research and Treatment of Cancer (EORTC) to conduct a survey of its member organisations to map the legal provisions in social and employment law afforded to people with cancer. The survey also identified the challenges faced by people with cancer in different member states: those undergoing acute treatment, the survivors and those with advanced and metastatic cancers, including people who care for them – their carers.

The results of this survey could not be published before the COVID-19 pandemic that affected most of our planned activities. However, ECPC is now looking into updating the survey of 2018 with post-pandemic data and publish our long-awaited Europe of Social Disparities in Cancer White Paper.

ECPC believes in the need to build a better picture of social disparities that exist in Europe. By building the knowledge on the current state of a range of social and employment matters in each Member state, ECPC will equip advocacy efforts at EU-level, but also empower member organisations at national level, to request commitment and action from the new European Parliament.

Objectives

Despite several initiatives at EU level, such as the European Partnership for Action Against Cancer (EPAAC) and the Joint Action on Cancer Control (CanCon) where the White Paper directly informed select CanCon recommendations for the development of national cancer plans. ECPC has been working with the oncology community to drive implementation of the CanCon recommendations through initiatives such as the Innovative Partnership for Action Against Cancer (iPAAC) and is building the evidence base for the capacity-building of ECPC member organisations' policy and advocacy capabilities. The White Paper 'Challenging the Europe of Disparities' is and will remain a powerful resource for shedding light on inequalities faced by cancer patients in Member States. The Paper will be a good data repository to be used to inform the European Commission Cancer Inequalities Registry that was launched in early 2022.

ECPC aims at further identifying existing inequalities at EU level among different Member States, social and ethnic groups to support our members to advocate for a Europe of equality in cancer care, contribute to the capacity building at national level and increase awareness at all levels.

Actions

ECPC will put its effort in finalising the long-awaited White Paper " Europe of Social Disparities". The White Paper will include provisions in the areas of social protection (such as inability/disability recognition), social benefits, employment rights, access to loans and insurance, amongst others. It will, as well, seek to identify the differences that exist amongst the member states in legal protections for people with cancer and their carers and identify key policy recommendations which could be implemented at the EU-level to bring greater equality to all European citizens and reduce the burden of social disparities.

The ECPC Legal Network for Cancer Patients will be involved in the preparation,

production, and execution of this White Paper. The ECPC Legal Network for Cancer Patients brings together a solid base of legal practitioners to share their legal competences on a volunteer basis in order to benefit people with cancer.

The White Paper will be launched in the European Parliament. The event will be chaired by MEP Cristian Busoi, Chair of the Challenge Cancer Intergroup. Other invitees will include members of the Challenge Cancer Intergroup and BECA Committee.

ECPC will draft, as well, a Call to Action with policy recommendation and concrete actions addressed to the European Commission and to the Member States to make the most of the valuable data included in the White Paper. This Call to Action will call on one hand on the Commission to include all the necessary legal documentation for each Member State to complete the results included in the White Paper and, on the other hand, on the Member States to take measures to address the gaps described at the national level.

Deliverables

- Europe of Social Disparities in Cancer White Paper
- Event in European Parliament to launch "Challenging the Europe of Social Disparities in Cancer"
- Call to action with policy recommendations at the EU level

Timeframe

- Month 1- 2: Questionnaire on legal provisions in the areas of social protection
- Month 2: Analysis of results from questionnaire
- Month 2-3-: Finalisation of the White Paper
- Month 4: Launch of "Europe of Social Disparities White Paper" in the European Parliament
- Month 4: Face-to-face meeting with the EU Health Commissioner Stella Kyriakides to discuss the data presented in the White Paper
- Month 4: Call to Action draft for the European Commission and Member States
- Month 4-5: Literature review and data analysis by the European Commission to complement the results presented in the White Paper
- Month 6-12: Dissemination of the findings at both the EU and national level
- Month 7-12: Develop fact sheets/infographics to raise awareness on the gaps at the national level
- Month 9-12: Translate the factsheets/infographics in at least 2 languages.

2.10 Palliative and complementary care

Duration: January 2023 – December 2023

Context

According to the World Health Organization (WHO), Palliative care is defined by an approach that improves the quality of life of patients and their families who are facing the problems associated with a life-threatening illness. The approach can be through prevention and relief of suffering by either early identification and assessment or treatment of pain and other physical, psychosocial and spiritual problems. This approach very often also includes complementary care, meaning an additional treatment option outside of the conventional medical treatment, such as yoga, meditation, massage and acupuncture. These types of complementary palliative treatments may help decrease stress and anxiety as well as side effects of treatments and help improve quality of life.

Palliative complementary care could help improve the holistic approach to treatments, meaning seeing the patient as a whole and its surroundings as part of the treatments as well. To improve quality of life, there needs to be a consideration of the patients' day to day routines, stress levels and emotions as well as the molecular chemistry of the patient from a medical point of view. Meditation, Yoga and other complementary care practices may have an impact on stress levels which, in turn, can also improve treatments adherence and outcomes. To improve patient outcomes a better emphasis must be placed on quality of life instead of only treating the patient within a multidisciplinary team to meet the different needs of the patient.

Objectives

ECPC will make sure that palliative and complementary care is focused on improving the quality of life for people living with cancer and that they receive palliative care at any time from the point of diagnosis, throughout treatment, and survivorship. More information will help cancer patients and their caregivers learn more about palliative care.

Actions

ECPC will try to put the person-centred palliative and complementary care model into the spotlight of the EU agenda by creating a working group putting all relevant stakeholders together to explore the current situation in Europe, new thinking, shared purpose, and agreed ways of working and partnership synergies. The working group will identify all the available forms of Palliative and complementary care including the digital ones, will try to understand the level of knowledge and uptake across Europe, identifying the gaps, organize a European campaign, prepare and disseminate 2 fact sheets in several EU languages (one for the general public, cancer patients and caregivers) and one for the policy makers. The findings will be presented at a European Parliament event or if the situation does not permit, in the form of an online webinar. A social media campaign will also be launched.

Deliverables

- Working group established with several relevant stakeholders
- Social media campaign
- Preparation of 2 factsheets
- EU Parliament event

Timeframe

- Month 1: Establishment of a working group
- Month 1-6: Launching of survey to identify palliative and complementary care outcomes from ECPC members
- Month 6-8: Preparation of the campaign and the factsheets
- Month 6-8: Joint Letter with relevant stakeholders
- Month 9-10: EU Parliament event, Euractiv or Euronews

3. Health and Research

3.1 Big Data and Personalised Medicine

3.1.1 QUALITOP

Title: Monitoring multidimensional aspects of QUAlity of Life after cancer ImmunoTherapy – an Open smart digital Platform for personalised prevention and patient management

Type: Horizon 2020

Duration: 2020-2024

Lead Coordinator: HOSPICES CIVILS DE LYON (HCL)

Aim: QUALITOP aims at 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. Through causal inference analyses, QUALITOP will identify the determinants of health status regarding IR-AEs and define patient profiles in a real-world context. For this, heterogeneous data sources (big data), both retrospective and prospective –collected for QUALITOP from clinical centres in four EU countries—will integrate lifestyle, genetic, and psychosocial determinants of QoL. 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' behaviour, a better IR-AEs prediction, and an improvement of care coordination will help analysing through simulation modelling approaches the gain in cost-effectiveness. Guidelines will be issued over the short and long-term.

What ECPC does:

ECPC 's role is to continuously disseminate the communication around the Qualitop project as it progresses by overseeing and updating the Qualitop social media channels and website and ensuring the communication objectives are being reached. ECPC will collaborate closely with the project manager and the project coordinator and will involve each consortium member to implement the dissemination plan.

3.1.2 Instand-NGS4P

Title: Integrated and standardized NGS workflows for Personalised Therapy

Type: IMI project co-funded by Horizon2020

Duration: 2020-2024

Lead Coordinator: MEDIZINISCHE UNIVERSITAT - GRAZ, AUSTRIA

Aim: INSTAND-NGS4P is an EU-funded Pre-Commercial Procurement (PCP) project for 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.

What ECPC does:

ECPC will be strongly involved in education, training and dissemination to the public. For patients: ECPC and FAVO will prepare specific materials with adapted languages to inform patients (minor, adult and their family members) on the activities of the various aspects and stages of the project. This type of material will ensure a better understanding of the clinicians' diagnostics by the patients and potentially by its family members (paediatrics and adult patients). ECPC will be part of the Patient Needs Consensus Board, participating in the monitoring of patient requirements and information during the study and ensuring the ethical management of privacy and security of patients' data. ECPC has contributed to evaluate the project providers for the different sections for the implementation of the technical project and will participate in the patients board monitoring the progression through the different phases of the study. ECPC has also contributed to the generation of a children's consent form including the special requirements and needs for underage cancer patients.

3.1.3 LEGACy

Title: CELAC and European consortium for a personalised medicine approach to Gastric Cancer

Type: Horizon 2020

Duration: 2019-2022

Lead Coordinator: INCLIVA Health Research Institute

Aim: LEGACy will use a personalised approach that will improve gastric cancer treatment by improving the knowledge of which treatment will work best for each patient. Additionally, the project will identify and educate those with higher risk of getting gastric cancer earlier and improve the early detection of gastric cancer when the prognosis is still higher.

What ECPC does:

ECPC leads the project's work on communication and dissemination, ensuring

an effective external stakeholder network and the engagement of patients and the public. ECPC developed and maintains a project website and multiple social media platforms, and disseminates a triannual newsletter and press releases. ECPC is also responsible for patient information, reviewing informed consent forms, involving expert patient advocates in the online training courses, and hosting a final stakeholder event at the completion of the project.

3.1.4 BD4BO PIONEER

Title: Prostate cancer diagnosis and treatment enhancement through the power of Big Data in Europe

Type: Funded by the Innovative Medicines Initiative (IMI) 2 Project

Duration: 2018-2023

Lead Coordinator: STICHTING EUROPEAN UROLOGICAL FOUNDATION (EAU)

Aim: 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.

What ECPC does:

ECPC is contributing to the overall project by providing a voice to prostate cancer patients through offering expert patient input and advice during the entire life cycle of the project. The participation of ECPC ensures that the patients engage in their disease management, thus leading to better treatment adherence and improved Quality of Life (QoL). This includes and is not limited to reviewing informed consent forms, surveys, study protocols and guidelines, setting up patient focus groups, drafting patient information leaflets and brochures, and the successful communication and dissemination of the project's deliverables. ECPC is also working to ensure that the visual identity of PIONEER is aligned with the branding of the DO-IT communication and support action for all BD4BO projects supported by the IMI. ECPC forms part of the follow-up project that includes breast and lung cancer besides prostate cancer that is called OPTIMA and started in 2021.

3.1.5 Lifechamps

Title: Prostate cancer diagnosis and treatment enhancement through the power of Big Data in Europe

Type: Horizon 2020 Project

Duration: 2020-2022

Lead Coordinator: Aristotle University of Thessaloniki, Greece

Aim: LifeChamps delivers a novel, context-aware and large-scale analytics framework capable of delivering multi-dimensional Quality of Life (QOL) support to all the different cancer life champions during and after their treatments. LifeChamps is providing support to middle aged and older (pre-frail and frail) cancer patients, as well as their caregivers and healthcare professionals, with an integrated Big Data-driven solution capable of improving their QOL via a timely and more accurate clinical decision support at the point of care. Its Artificial Intelligence (AI) and analytics engine, running both at the cloud and at the mobile edge, can determine accurately which factors affect the oncological patients' QOL the most, during and after their treatment. Furthermore, complemented by a health recommender system LifeChamps offers personalised healthcare services (such as symptom monitoring, treatment and rehabilitation) to these patients and their caregivers. Finally, a multi-factorial frailty model will allow the stratification of sub-clinical frail groups of geriatric cancer patients towards more personalised treatment.

What ECPC does:

In this project, the European Cancer Patient Coalition (ECPC) will lead liaison and interaction with relevant stakeholders from industry, SMEs, patients, healthcare professionals and policy makers at EU and country level. ECPC will also participate in the identification/establishment of the health needs, priority outcomes, and care requirements of end-users/stakeholders at the post-cancer treatment period, as well as their views, preferences and expectations from the developed LifeChamps components.

3.1.6 T2EVOLVE

Title: Accelerating Development and Improving Access to CAR and TCR engineered T cell therapy

Type: funded by the Innovative Medicines Initiative (IMI) 2 Project

Duration: 2021-2025

Lead Coordinator: Universitaetsklinikum Wuerzburg - Klinikum Der Bayerischen Juliusmaximilians- Universitat (UKW)

Aim: Immune cells that are empowered by gene-engineering to seek and destroy cancer cells (engineered T cell therapy) constitute a transformative novel treatment that has the potential to cure cancer. Multiple new versions of this therapy are being developed for distinct types of cancer but their introduction into clinical practice is hampered by a lack of standardized and validated models to predict safety and efficacy, customized manufacturing and monitoring to scale up production and clinical use to industry standard, and strategies for optimal patient conditioning. The T2EVOLVE consortium unites scientists and physicians, regulators and policy makers, SMEs, and patient stakeholders to tackle these challenges in an orchestrated multi-disciplinary multi-stakeholder approach. A core feature of this approach will be the embedding of patient stakeholders as contributing members of the team across all levels of the R&D process.

The overall aim is the development of an innovation ecosystem that will accelerate the process of developing engineered T cell therapy in the EU. The project will deliver novel tools for education and for improving the communication between healthcare providers and patients, optimized laboratory models that can help determine how safe and effective new therapies with engineered T cells are, standardized methods in which these therapies are produced and monitored during treatment. The consortium members are innovators and pioneers in this field that are dedicated to bringing the EU to the forefront of the global engineered T cell therapy movement. This effort will ensure that EU citizens will continue to have access to the most innovative and best-available medical care, provide guidance on how to implement this novel treatment into the EU health care system in a sustainable way, and secure a leading role for Europe in this emerging field in medicine and science, the economy and society.

What ECPC does:

ECPC is leading the activities of WP2 on Patient involvement to assure that the perspectives of cancer patients are considered in a meaningful way throughout the entire R&D process. Ensure adequate communication on engineered T-cell therapies to patients and their family/informal caregivers, ensure that HCPs are sensitised to patient needs, propose solutions for equitable patient access to engineered T cells and guarantee broad patient access to engineered T cells.

3.1.7 Intervene

Title: International consortium for integrative genomics prediction

Type: Horizon 2020 Project

Duration: 2021 – 2025

Lead Coordinator: UH-FIMM, University of Helsinki

Aim: 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. The project aims to integrate longitudinal and disease-relevant omics data into genetic risk scores. 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).

What ECPC does

To evaluate the clinical and economic impact of using polygenic risk information for decision support and primary prevention of breast cancer. ECPC forms part of the board that designs and determines the best way to implement this technology in the prevention and therapy of breast cancer.

Counselling first-degree relatives of breast cancer patients. ECPC will participate in providing clear, fair and defined information to families about the benefits, limitations and potential consequences of applying this technique.

Qualitative assessment of perception of genetic scores and genetic reporting tools. In this task ECPC will contribute to the evaluation of the results after implementing this technique for specific cancer types.

Framework for trustworthy AI and Ethical guidance principles for genetic score-based risk prediction and personalised medicine. ECPC will have a role in defining a standard and easily reproducible way to help the implementation of this genetic prediction tool.

Internal project management and coordination. Contribution to the integration of the different WPs and the promotion of collaborative networks within the consortium.

Coordination of the periodic technical and financial reporting. Facilitate the processing and defining the ways to report for the consortium members.

Planning and hosting of project meetings. Arranging online and face to face meetings within the consortium, facilitating the communication amongst partners and WPs.

Co-creation of a communication and dissemination plan. Regular meetings with members of this WP to generate communication channels that allow the monitoring of the progression of the different WPs and the dissemination of the hallmarks to external audiences.

Communication and dissemination activities. Arrangement of webinars, workshops, surveys and other tool-kits to make all the achievements and developments visible to all consortium partners and external stakeholders.

Plan for exploitation of project results. Designing the best channels to use and benefit from the project's results.

3.1.8 **TIGER**

Title: Proof of Principle of the best-in-class therapeutic mRNA cancer vaccine

Type: Horizon 2020 Project

Duration: 2021-2025

Lead Coordinator: ETHERNA IMMUNOTHERAPIES (eTheRNA)

Aim: TIGER delivers proof of principle (PoP) in humans for a novel best-in-class mRNA cancer vaccine platform optimized for intravenous (IV) administration, with the aim to show major clinical efficacy. The antigens used for the PoP consists of mRNAs encoding the proteins E6 and E7 of Human Papilloma Virus strain 16 (HPV16), and TriMix mRNAs that stimulate dendritic cells to start strong T cell responses. The mRNAs will be formulated in a novel patented lipid nanoparticle format shielding the mRNA, and delivering it to immunoactive antigen presenting cells, vastly enhancing T-cell response. Safety and best-in-class efficacy of our IV mRNA product have been demonstrated in rodent experiments. Furthermore, preclinical to clinical translation has been shown for our TriMix based vaccines using different delivery strategies. Based on the preclinical and prior clinical data, our platform has the potential to cure cancer patients. The PoP study will be in

patients with recurrent HPV16 positive cancer, which is categorised as a non-communicable disease by the WHO, without and with a PD-1 checkpoint inhibitor. Safety, immunogenicity and clinical benefit will be key endpoints of the study. Biomarker and PROM research will allow future informed therapeutic and care decisions by both patient and care team. Recruitment and stratification plans will be in place. Interactions with regulatory, reimbursement and ethical authorities together with patients and carers will help laying out the route to the patient not only for our product but also for all other mRNA cancer vaccines. Additionally, the project encompasses all essential elements for preparing therapy validation in later stage clinical studies, while adressing patient needs, values and choices. Upscaling mRNA vaccine GMP-production will enable these further clinical studies. Once validated, our platform will be easily translatable to a wide range of cancers using other tumour antigens, be they TAAs or neoantigens.

What ECPC does

ECPC is involved in WP1 (Regulatory and ethics management, Patient Reported Outcome Measures, and market access strategy) and in WP5 (Dissemination and Communication).

3.1.9 OPTIMA

Title: Optimal treatment for patients with solid tumors in Europe through Artificial Intelligence

Type: Funded by the Innovative Medicines Initiative (IMI) 2 Project

Duration: 2021-2026

Lead Coordinator: University of Aberdeen

Aim: 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 trhough Artificial Intelligence to achieve the best ways for early diagnosis, personalised therapy.

What ECPC does

ECPC is contributing to the overall project by providing a voice to prostate , breast and lung cancer patients through offering expert patient input and advice during the entire life cycle of the project. The participation of ECPC ensures that the patients engage in their disease management, thus leading to better treatment adherence and improved Quality of Life (QoL). This includes and is not limited to reviewing informed consent forms, surveys, study protocols and guidelines, setting up patient focus groups, drafting patient information leaflets and brochures, and the successful communication and dissemination of the project's deliverables. ECPC is also working to ensure that the visual identity of PIONEER is aligned with the branding of the DO-IT communication and support action for all BD4BO projects supported by the IMI.

3.1.10 CGI-Clinics

Title: Data-driven cancer genome interpretation for personalised cancer treatment

Type: Funded by European Health and Digital Executive Agency

Duration: 2022-2027

Lead Coordinator: FUNDACIO INSTITUT DE RECERCA BIOMEDICA (IRB BARCELONA) (IRB)

Aim: CGI-Clinics will build eduCGI, an app to help them understand the information gained through interpretation of their tumors, facilitating informed discussions with clinicians and sharing their data for research. Ultimately, the project is built to inform policy-makers on cancer management and empower patients.

What ECPC does

ECPC is going to participate in different work packages in this project. Enforcement of patient empowerment and policies, monitoring that patient data is handled using best practices protocols and the management and sharing of the data respects patient's anonymity and rights of ownership are roles where ECPC will be involved. We will also be part of the communication and dissemination team and the coordination and exploitation of the project.

3.1.11 AIDAVA

Title: AI powered Data Curation & Publishing Virtual Assistant

Type: Funded by European Health and Digital Executive Agency

Duration: 2022-2026

Lead Coordinator: University of Maastricht (UM)

Aim: AIDAVA has the potential to democratise participation in data curation & publishing by citizens/patients leading to overall savings in health care costs (through disease prevention, early diagnosis, personalized medicine) and supporting delivery of the European Health Data Space.

What ECPC does

ECPC will participate in the recruitment and follow up of patients' use cases, providing some patients that will work as advisors for the development of the project. It will also be part of the regulation regarding the management of data taking care of patients rights and anonymity. ECPC will also have an important role in the communication and dissemination of the project and will contribute to the management and scientific coordination of the consortium.

3.1.12 EOSC4Cancer

Title: A European-wide foundation to accelerate Data-driven Cancer Research

Type: funded by European Health and Digital Executive Agency

Duration: 2022-2025

Lead Coordinator: BARCELONA SUPERCOMPUTING CENTER - CENTRO NACIONAL DE SUPERCOMPUTACION (BSCCNS)

Aim: EOSC4Cancer brings together a comprehensive consortium of cancer research centres, research infrastructures, leading research groups, hospitals and supercomputing centres from 14 European countries. To make the developments sustainable, these will be offered as part of the research infrastructures partners services portfolio, in connection with the EOSC ecosystem and to serve the European Cancer Mission, which will be possible via the engagement with large international coalitions, e.g. ICGC-Argo, GA4GH, 1+MG/B1MG, Cancer Core Europe, European Cancer Information System, European Network of Cancer Registries, Innovative Partnership for Action Against Cancer Joint Action and patients/survivors associations.

What ECPC does

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 patients' needs. ECPC will contribute to enforce the patient engagement and improve the trust, transparency and bias related to AI use in cancer diagnose and treatment.

3.2 Patients and Caregivers

3.2.1 MyPath

Title: Developing and implementing innovative Patient-Centred Care Pathways for cancer patients

Type: Funded by European Health and Digital Executive Agency

Duration: 2022-2027

Lead Coordinator: OSLO UNIVERSITETSSYKEHUS HF (OUS)

Aim: 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.

What ECPC does

ECPC will participate in three work packages. It will be an essential contributor to co-design the structure and contents besides in the dissemination and communication of the project. ECPC will also have a major role in the coordination and the networking of the consortium.

3.2.2 DIAdIC

Title: Dyadic Psychosocial and Educational Interventions for People with Advanced Cancer and their Informal Caregivers.

Type: Horizon 2020 Project

Duration: 2019-2023

Lead Coordinator: Vrije Universiteit Brussel

Aim: DIAdIC will develop and evaluate two different methods of administering psychosocial and educational interventions: a face-to-face method provided to patient and caregiver at home by a specially trained professional and a self-administered electronic tool. Both interventions are aimed at the patient-caregiver dyad (something consisting of two parts or persons, from Latin/Greek duas or dyás) and will be available across Europe to provide good psychosocial and educational support to patients and their family caregivers.

What ECPC does

ECPC leads the project's work on dissemination and communication, ensuring engagement with the public, patients and other stakeholders. ECPC designed the project's visual identity, developed and maintains a project website and multiple social media platforms, and disseminates a biannual newsletter and press releases. ECPC is also helping in drafting implementation guidelines for the DIAdIC interventions to ensure further implementation, writing a position paper with policy and awareness recommendations, and hosting the final stakeholder event at the completion of the project.

3.2.3 Preferable II

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

Type: Funded by European Health and Digital Executive Agency

Duration: 2022-2027

Lead Coordinator: UNIVERSITAIR MEDISCH CENTRUM UTRECHT (UMCU)

Aim: PREFERABLE-II contributes to improving the QoL of cancer survivors by lowering the burden of side effects, while also improving availability, access and awareness of exercise-based supportive care interventions.

What ECPC does

ECPC is part of the set-up and execution of a tele-system, LION-RCT that may guide and facilitate personalised sports programmes for patient survivors. Other roles will cover the analysis of the outcomes, the understanding of social and legal aspects of remote exercise for survivors and the communication of standards for exercise in oncology. In addition, it will contribute to the dissemination and exploitation of the project.

3.2.4 RELEVIUM

Title: Improving quality of life of advanced pancreatic cancer patients through an

AI-guided multimodal intervention, combining pain and cachexia management, nutrition, and physical activity

Type: Funded by European Health and Digital Executive Agency

Duration: 2022-2026

Lead Coordinator: UNIVERSITAETSMEDIZIN DER JOHANNES GUTENBERG - UNIVERSITAET MAINZ (UMC-Mainz)

Aim: A five-centre randomized clinical trial (RELEVIUM-RCT) will evaluate the efficacy of the proposed personalised care plans for advanced pancreatic cancer patients (n=132) in terms of their QoL. Several secondary outcomes will be investigated, such as the cost-effectiveness of the intervention, its potential in increasing health equity and in relieving the stress burden on the patient families. The study outcomes will result in recommendations for integrating remote monitoring and improving QoL outcomes in palliative care for advanced pancreatic cancer.

What ECPC does

ECPC will contribute to the analysis of the needs and the technology deployment. It will participate in the dissemination and exploitation planning of the project.

3.3 Palliative Care

3.3.1 Palliative Sedation

Title: The use of proportional palliative sedation for the relief of refractory symptoms: an international multicentre study

Type: Horizon 2020 Project

Duration: 2019-2023

Lead Coordinator: Radboud University Medical Centre

Aim: 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 is investigating current practices and guidelines, as well as conducting a clinical study into PS, measuring patient comfort as the primary outcome, which is being carried out at five European palliative care centres. Furthermore, the Palliative Sedation project is formulating recommendations for an updated framework for the use of sedation in palliative care, working towards producing a free online educational 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.

What ECPC does:

ECPC sits on the Palliative Sedation Scientific, Clinical and Ethical Advisory Board to encourage policy-makers, researchers, doctors and industry to recognise

cancer patients as co-creators of their own health. ECPC directly engages with expert patient representatives to ensure that research is designed and adapted to better respond to patient needs. Through its members, ECPC contributes to a PS country survey and supportive interviews that reveal the level of integration of clinical sedation guideline recommendations in healthcare practice across Europe. ECPC also supports the revision of the current European Association for Palliative Care (EAPC) framework for PS, and the design of the PS educational programme and e-book containing clinical and ethical guidance that can be adopted for PS. ECPC will partner the dissemination of the project outcomes to patients, general public, industry and policy-makers.

3.3.2 PAL-CYCLES

Title: PALliative Care Yields Cancer welLbEing Support

Type: Funded by European Health and Digital Executive Agency

Duration: 2022-2027

Lead Coordinator: RADBOUD UNIVERSITAIR MEDISCH CENTRUM

Aim: 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.

What ECPC does:

ECPC will participate in the development and local adaptation of the project's framework intervention. It will also collaborate to reduce barriers and facilitate the planning and developing of the intervention using a multicenter case study method. The participation will cover the dissemination and exploitation of the project as well.

3.3.3 Painless

Title: Pain relief in palliative care of cancer using home-based neuromodulation and predictive biomarkers

Type: Funded by European Health and Digital Executive Agency

Duration: 2022-2027

Lead Coordinator: UNIVERSIDAD DE SANTIAGO DE COMPOSTELA (USC)

Aim: 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; analyse the possibilities of implementation in different European healthcare systems and results exploitation; and undertake an ambitious dissemination and communication strategy. We will also propose a wide range of measures to ensure compliance with the highest ethical standards.

What ECPC does:

ECPC will participate in communication and dissemination activities and in the coordination and management of the project. We will supervise the compliance with the ethical requirements and the respect of the patient's rights.

3.3.4 INSPIRE

Title: Integrated short-term palliative rehabilitation to improve quality of life and equitable care access for people affected by incurable cancer

Type: Funded by European Health and Digital Executive Agency

Duration: 2022-2026

Lead Coordinator: King's College London

Aim: 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.

What ECPC does:

ECPC will play a broad role in this project, participating in the development of the interventions and coordination of the main trial. It will evaluate the equity and inclusiveness in the accessibility during the process and implementation of the study. It will also contribute to synthesize the different international approaches to palliative care and create a consensus guideline and protocol in an international framework. Together with EAPC will ensure the dissemination and explotation of the study.

3.4 Treatments

3.4.1 Immune-Image

Title: Specific Imaging of Immune Cell Dynamics using novel tracer strategies

Type: Funding from the Innovative Medicines Initiative 2 Joint

Duration: 2019-2024

Lead Coordinator: Amsterdam UMC

Aim: Project 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.

What ECPC does:

ECPC supports communication and dissemination of the Immuno-Image project's outcomes towards cancer patients and cancer organisations during the duration of the whole project. ECPC is a major contributor in the development of a survey that will help to define the knowledge and gaps that patients have over what immune-therapy and the use of imaging technique may provide in the improvement of their quality of life. This involves conveying information about the trials to confirm safety and to evaluate the clinical potential of novel immune-tracers to ECPC cancer patient community and other relevant European patient organisations. ECPC will also be involved in the management and regulation of data storage and analysis enablement. ECPC involves multiple patient organisations who would benefit from the project outcomes.

3.4.2 ImmunoSABR

Title: 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

Type: Horizon 2O20 Project

Duration: 2017-2023

Lead Coordinator: Universiteit Maastricht (UNIMAAS)

Aim: The main objective of ImmunoSABR will be to obtain clinical proof of concept for our bi-modal curative treatment strategy, by conducting a randomised phase II clinical trial in patients with less than 10 metastases from Non-Small Cell Lung Cancer. We hypothesized ImmunoSABR will prolong progression-free survival (PFS) while maintaining quality of life and at the price of only mild, transient toxicity.

What ECPC does:

ECPC supports the management, dissemination and exploitation of the ImmunoSABR project. This entails conveying information about the ImmunoSABR trial to our own network, other relevant European patient organisations, and the public. ECPC is also organising a dedicated patient consultation session to discuss the ImmunoSABR trial, providing a platform for panel discussions with patients regarding clinical trial design. ECPC has already provided input for the development of the project's informed consent forms and the related patient brochure. Furthermore, ECPC is hosting the final ImmunoSABR conference combined with a stakeholder workshop at the European Parliament to disseminate project results.

3.4.3 4.UNCAN.eu

Title: A Coordination and Support Action to prepare UNCAN.eu platform

Type: Horizon Coordination and Support Actions

Duration: 2022-2023

Lead Coordinator: INSTITUT NATIONAL DE LA SANTE ET DE LA RECHERCHE MEDICALE (INSERM)

Aim: The 15-month coordination and support action "4.UNCAN.eu" will generate a strategic agenda to launch UNCAN.eu, a European initiative to understand cancer proposed by the Mission Board and the European Beating Cancer Plan. This research agenda will be built with the final aim of achieving a new breakthrough in cancer prevention and treatment that will contribute to saving European citizens' lives and help ensure an optimal quality of life to disease survivors.

What ECPC does:

ECPC is involved in work package 4 that includes the role of European patients and citizens in cancer research.

3.4.3 CanServ

Title: Providing cutting edge cancer research services across Europe

Type: HORIZON Coordination and Support Actions

Duration: 2022-2025

Lead Coordinator: Biobanking and Biomolecular Resources Research Infrastructure, BBMRI ERIC (BBMRI)

Aim: CanSERV will offer key state-of-the-art RI services necessary to tackle all aspects and challenges of the development pipeline for oncology, as well as the translation to the clinic - from bench to bedside and back to bench- and the engagement with future users.

What ECPC does:

ECPC will play a key role in this project, contributing to address social inequalities around Europe, promoting the access to cutting-edge services and tool-kits to better inform patients about public health measures and the accessibility to new advances in cancer research.

3.5 Scientific Committee and Advisory Role

3.5.1 EUCANCan

Title: European-Canadian Cancer Network

Type: Horizon 2020

Duration: 2019-2022

Lead Coordinator: Barcelona Supercomputing Center

Aim: EUCANCan aims at supporting and enhancing modern oncology, by implementing a cultural, technological and legal integrated framework across

Europe and Canada, to enable and facilitate the efficient analysis, management and sharing of cancer genomic data.

This cooperative framework is not only expected to immediately contribute to improve biomedical research in cancer, but to also serve as a model for globalizing and enriching personalised medicine initiatives, allowing the exchange of data, clinical experience and information across different national health systems.

What ECPC does:

ECPC sits on the EUCANCan Advisory Board to ensure the project activities are in line with the needs of cancer patients by actively participating in discussions and providing feedback and input on research activities and outputs.

3.5.2 PREDICT

Title: A new era in personalised medicine: Radiomics as decision support tool for diagnostics and theragnostic in oncology

Type: funded by the Marie Skłodowska-Curie Actions, part of the EU's Horizon 2020 Programme

Duration: 2017-2021

Lead Coordinator: Maastricht University

Aim: PREDICT educates 15 Early Stage Researchers (ESRs) in the fields of radiomics and personalised medicine, training them to analyse large amounts of radiographic images to determine tumour heterogeneity and predict how patients will respond to treatment.

What ECPC does:

ECPC provides the Early Stage Researchers with training courses and workshops on communicating complex research results to a public audience, understanding the patient perspective, and scientific writing. ECPC uses its communication channels to share information about the project, its results and its participants. ECPC is represented on the Project Advisory Board to monitor project progress and provide input on the design and overall direction.

3.5.3 HTx

Title: Next Generation Health Technology Assessment to support patient-centred, societally oriented, real-time decision-making on access and reimbursement for health technologies throughout Europe

Type: Horizon 2020 Project

Duration: 2019-2023

Lead Coordinator: Utrecht University

Aim: HTx will facilitate the development of methodologies to deliver more customized information on the effectiveness and cost-effectiveness of complex and personalised combinations of health technologies. HTx will also provide methods to support personalised treatment advice that will be shared with patients and their physicians. Finally, HTx will, in close collaboration with the European Network for HTA (EUnetHTA) and its stakeholders, pilot the implementation of these methods in Europe.

What ECPC does

When the HTx project will hold a stakeholders' events, a fellowship programme will allow patients' advocates to attend the event and to engage directly with the project team. When HTx will present its findings to other conferences of interest, the same fellowship programme will help dedicated patient advocates attend the conference to listen to the presentations and to interact with the audience.

ECP sits on the project's Stakeholder Advisory Board, the HTx Forum. ECPC ensures the project activities are in line with the needs of cancer patients by actively participating in discussions and providing feedback and input on research activities, use cases and outputs.

4. Capacity Building

4.1 Knowing our Members

4.1.1 Update and development of a professional database

Duration: 12 months

Context

ECPC membership and partner lists have grown tremendously in the past years and the current excel database is not sufficient anymore to manage ECPC contacts in an efficient and effective manner. At this stage, it is essential to envision the future, and this can only be feasible through the full digitalization and update of our membership database.

Objectives

An updated and professional database will benefit all work areas of ECPC and will facilitate a closer relationship with members and partners keeping track record of their work and common field of interest. This will enable ECPC to quickly identify resources and needs, collecting and accessing relevant information, such as facts and figures, events, grants, campaigns, best practices, tools and training opportunities.

Actions

- A dedicated staff is now appointed to contact each Member to gather updated contact details and relevant documents
- A professional and tailored database of Members meeting ECPC's specific needs will be developed: A tool that would gather all ECPC members' contact details within a one-stop-shop for all ECPC Board Members and Secretariat to navigate and have access to.

Timeframe and milestones

- Month 1: Develop a capacity building and membership plan
- Month 2-4: Quality check and development of the database
- Month 4-10 Delivering the database populated with updated information
- Month 11-12 Testing the database, troubleshooting and training on how to make the most out of it
- Month 12 Launch of the new database

Deliverables

- Capacity building and membership plan

- Professional Member database delivered
- ECPC Board Members and Secretariat training on how to best use the Members' platform

4.1.2 Survey on Members' needs

Duration: 6 months

Context

Currently ECPC communicates with its members during the Annual Congress, the General Assembly, via mailings, the newsletter, ad hoc requests and on social media. These actions are not enough to gather feedback on ECPC support to its members and to create a constructive dialogue. A survey is an essential and engaging tool that will help ECPC Board Members and Secretariat increase the engagement with all our member organisations.

Objectives

Having an in-depth knowledge of all its members' needs, specificities and interests, will radically improve ECPC's legitimacy to accurately represent its members and to become a stronger association and will help strengthen ECPC membership by identifying members' strengths, challenges and needs. It will also make members' feel their voices are heard and transmitted into our policy actions on a European and then, on a national level. ECPC will ensure that our Members point out the separate challenges they are facing on a national level, and provide support by translating their problems into concrete policy actions.

Actions

- Develop a membership survey
- Collect the answers
- Review and analysis of the answers
- Report and address the finding
- Preparing a Communications Toolkit on how our members should best tackle their issues on a national and European level: these issues can be addressed via their dissemination on social media, local and European media, as well as through raising them during milestone dates or via ECPC's annual campaigns.

Timeframe and milestones

- Month 6 – 8 Dissemination of the questionnaire to members
- Month 9 Analysis of the answers
- Month 10 – 12 Drafting the report and recommendations pointing out mainly the ways to tackle these issues

Deliverables

- Table summarizing the answers, including statistics and key words
- Report of the survey
- Recommendations for future actions, services, tools designed for ECPC's members

4.1.3 Members' section in monthly newsletter

Duration: 12 months

Context

Taking into account the existing way of communication to our members analysed above, the addition of a Members' only section in ECPC's monthly newsletter will increase engagement, as well as their visibility within ECPC and on a European level.

Objectives

The monthly newsletter has been used as one of our main tools in terms of internal communication to our members. However, we need to ensure that members' engagement on the content is increased. For this reason, the introduction of a specific area tailored for our members will increase the WIIFM approach (What's In It For Them), as well as their visibility within the members community.

Actions

- On a monthly basis and, upon Board approval, to circulate a document or a Thematic that would inspire our members to draft content for the Members' Section;
- Ensure that all Members are represented in our newsletters and increase their engagement.

Timeframe/Milestones (set on a monthly basis as per each newsletter)

- Until mid of each month, to circulate the thematic of the month;
- By the 25th of each month to agree on which Members' stories will be featured, so as to ensure equal and fair representation of them;
- By the end of the month, to edit the content shared by our members and share it with them for approval.

Deliverables

- By the end of 2022, to circulate a survey or questionnaire asking our Members of their areas of interest or what they would be interested in contributing on the ECPC newsletter;
- From January and onward, to include a Members' Only section in the beginning or end of ECPC's newsletter.

4.2 Bonding with our Members

4.2.1 ECPC Conference

Duration: 6 months

Context

The ECPC Conference is the fundamental event where ECPC meets all its members and partners. It is a unique opportunity for engagement, capacity building and networking. In 2022, the ECPC Conference was held in a hybrid form. For 2023, we expect it to be held on site. From 2023 and given the conditions, we aim to organize the meeting again onsite.

Objectives

- To create a sense of community within the organization through networking sessions, identifying new opportunities, listening to needs and specificities
- To give members new resources and ideas to work at home through a relevant and inspiring programme tailored to their needs
- To consolidate ECPC Conference profile making it the major event for cancer patients in Europe

Actions

- Identification of speakers and attendees, invitation, patronage requests
- If in person, selection of a venue, organization of accommodation and logistics of the event, including liaising with the attendees and the travel agency to book travels
- Drafting the agenda and inviting speakers creating targeted content for various audiences and scheduling it
- Promoting the event
- Partnering with an EU media outreach and press relations with national and sectoral media, scheduling interviews

Timeframe / milestones

- Month 1: Venue selection
- Month 2: Registrations open
- Month 3-4 Starting accommodation booking and preparing the administrative logistics of the Conference, so as to ensure the highest participation as possible
- Month 4-5 Draft programme and promotion of the event within our members, as well within the healthcare NGO section in Brussels and beyond for more visibility and engagement
- Month 6 Press relations and social media promotion and PR of the Conference

Deliverables

- Conference agenda
- Conference report
- Communications Toolkit

4.2.2 General Assembly

Duration: 6 months

Context

The General Assembly usually takes place right after the Conference to optimise costs. A general assembly is not just an administrative obligation. It aims at:

- Fostering a relevant, democratic and dynamic NGO, faithfully representing its members
- Showing them its work and the upcoming challenges
- Putting to vote important decisions such as the budget, the action plan, statutes changes, main political and strategic directions

For the 2022 edition, a hybrid form was organized on 28th May 2022, in Brussels Belgium. For 2023, the AGM will take place together with the ECPC Conference, onsite.

Objectives

- To increase the sense of ownership of members and their engagement on the ECPC community activities;
- To properly inform Full Members before the vote;
- To create the conditions for a proper and open debate before the vote;
- To increase attendance and voter turnout;
- To understand members' priorities and to check if they can be incorporated in the Action Plan for the upcoming years

Actions

- Send Full Members in depth background information about topics on the agenda
- Collect Full Members' questions and feedback
- Set up a Q&A Facebook live and Live Tweeting session with Board Members to answer questions and prepare for the AGM

Timeframe / milestones

- Month 1-2 Sending a mailing of information

- Month 3-5: Collecting questions through mailings, social media and on the website and promoting the Live Q&A video and/or Live Tweeting: two months prior to the event + reminders every two weeks and then every week. Circulate a questionnaire so that members can add their input and ensure their equal representation on this.
- Month 5-6: Live Q&A video

Deliverables

- Agenda of the General Assembly
- Circulate all relevant material prior to the General Assembly

5. Communications and Awareness Campaigns

5.1 Make Sense Campaign 2023 of head and neck cancer

Head and neck cancers (HNC) are one of the most common types of cancer, particularly 6th in Europe and 7th worldwide, with more than 150,000 new patients diagnosed every year. Despite its immense impact on health, there is little awareness among the public with many cases diagnosed at a late stage. Despite major advances in the treatments of head and neck cancer over the past decades, including new surgical tools and radio therapeutic modalities, the overall patient outcomes remain disappointingly unchanged.

Rationale

It has been observed that there is a significant lack of awareness of head and neck cancer in Europe. According to a pan-European survey conducted among the general public, 77% of respondents were unaware of the term 'head and neck cancer'. This survey also highlighted that there is a lack of knowledge among the general public of the risk factors, signs and symptoms of head and neck cancer, demonstrating a clear need for further education. As a result of this lack of awareness, it is unsurprising that nearly two thirds of all head and neck cancers are diagnosed at an advanced stage, while10% of patients show metastases at distant sites from the first presentation.

In recent developments in the area, the release of RARECARE data sheds a new light on head and neck cancers which involve several anatomically diverse sites, particularly oral cavity, pharynx, nasal cavity and sinuses, which are rare. The disease is complex, needs multimodality treatment, and the patient population is more likely to be elderly and have comorbidities and less social support. The study explores unsolved problems for rare cancers. Thus, the results suggest that diagnosis and treatment of head and neck cancers did not reach optimal standards in the EU countries considered in the study.

Research findings support policy decisions aimed at changing the health care organisation. Head and neck cancer patients should be referred to specialised centres or networks involving specialised centres because only the high-volume context can ensure the quality of care in the entire patient journey.

Additionally, now more than ever we should pay attention to cancer, cancer patients and survivors. As a result of diagnostic, screening and even treatment delays due to the coronavirus pandemic, a significant increase in the number of avoidable cancer deaths is expected already in the first six months of 2022. Moreover, the general public is unaware of the symptoms of HNC and reluctant to seek medical advice; coupled with COVID-19 the survey results we already obtained suggests we are facing a ticking time bomb for late diagnosis of this deadly disease.

Objectives

Objectives of the 2022 project are the following:

- To continue raising awareness, through a social media campaign (via Twitter, LinkedIn, Instragram and Facebook) and a webinar, of head and neck cancer across Europe among the general public, policymakers from the EU Institutions and national governments, and healthcare professionals, in order to improve outcomes through earlier diagnosis and treatment;
- To emphasize the fact that smoking and drinking can greatly increase the risk of developing head and neck cancer;
- To communicate and demonstrate the existing discrepancies in care between Member States and the need for adoption of standardised guidelines into national cancer plans – EHNS Head and Neck Cancer Survivorship guidelines (that should be launched in 2022 or in Q1 2023) and ESMO multidisciplinary care Head and Neck guidelines;
- To explore among relevant stakeholders and our Member Organisations how to best implement the survivorship guidelines at a national level using the updated White Paper on Head and Neck Cancer and factsheets;
- To promote research into technology and medicines that aid the screening, vaccination and treatment of head and neck cancer.

Head and Neck Fact Sheets

In preparation of the raising awareness campaign to be launched on the Head and Neck cancer Awareness Week, we will adapt the fact sheets based on current data in the post-pandemic era and we will translate in selected EU languages based on our members priorities and interest. The fact Sheets will be developed through the organisation of a focus group with our members to also identify with them the priority key audience.

Head and Neck Cancer Awareness Week

The social media campaign with impactful image and video messages of patients will be launched on social media during the Head and Neck Cancer Awareness Week (September 2023) to raise an awareness of the disease and to increase the attention of policy makers towards the topic. ECPC will develop a call to action dedicated to policymakers which will be distributed to members of the European Parliamentary Intergroup on Cancer, "Challenge Cancer" Intergroup, other Members of the European Parliament and to the European Commission Team working on the Europe's Beating Cancer Plan just before the launch of the campaign. At the same time, the updated factsheets and its translations will be distributed among ECPC members and stakeholders, general practitioners and the general public.

Webinar on Head and Neck cancer

With the Cancer Mission naming cancer a top EU priority for the European Commission and the European Parliament, and the ongoing coronavirus health crisis that is directly and indirectly having an impact on cancer patients' treatments and diagnosis, it is crucial that head and neck cancer remains high on the European agenda. As such, this event seeks to raise awareness about the disease and to address the objectives mentioned, through also launching a call to

action of six key action points that we want to seek support for:

1. *Actively engage in awareness campaigns on disease prevention and highlight the signs and symptoms of head and neck cancer*
2. *Support early diagnosis and referral to qualified healthcare professionals*
3. *Support a multidisciplinary treatment approach for head and neck cancer, by integrating experts across disciplines*
4. *Provide guidelines at EU level to ensure that all European citizens have equal access to the best available treatment under all circumstances, and support the dissemination of best practices in disease management across EU member states*
5. *Promote patient rehabilitation programme to drive engagement and adherence to ongoing treatment and care to ensure best possible health outcomes*
6. *Encourage further research on head and neck cancer to ensure better prevention strategies, treatment options and, ultimately, outcomes, for all patients*

In presenting an all-encompassing view, this meeting will comprise presentations from leading clinical and political figures within Europe, as well as patients and actors who can offer real life insights into head and neck cancer treatment and care.

Survivorship Guidelines - updated for 2023

Together with the HNC Society, ECPC will adapt the existing head and neck cancer survivorship guidelines based on the current state of play with the pandemic for a European audience. ECPC will ensure that head and neck cancer patients' voice is represented in the guidelines development, and we will include one of our members and HNC survivor to oversee this process.

Deliverables

- Updated fact sheets based on 2022 data and translation of the fact sheets on selected EU languages and their distribution to ECPC contacts and audience, including patient organisations, medical community, stakeholders from the EU Institutions and in Brussels, and policymakers from national governments.
- Webinar/event (agenda, invitation of speakers, invitation of participants, management of registrations, technical organization, moderation, report and follow up) in September 2023 during the Head and Neck Awareness Week
- Awareness campaign to promote the event and HNC awareness week on social media, including daily visual messages, quotes of HNC patients,
- Updated Campaign toolkit to maximize the interest of our members and stakeholders (social media calendar, toolkit, mailing) and its' promotion via ECPC's network
- Press relations to maximize media interest and coverage (press kit, press release, direct contacts with journalists and follow up, press cutting, identify campaign opportunities within Brussels media)

- Updated educational webpage on head and neck cancer on ECPC website
- Call for action to policy makers and our members organisations (on a European and on a national level) and its translation in selected EU languages
- Updated Guidelines with 2022 figures for HNC patients co-developed with patients to secure the patient perspective.

Timeline

- May-June: identify and outreach patient groups stakeholders and media to involve directly in the project, as well as identify the content for updating the fact sheets on current data to demonstrate the impact of the pandemic on tackling HNC
- July: organise focus group to update the fact sheets
- May – August: finalisation of materials, translations and graphic layout of any relevant materials for the campaign; finalisation of the outreach to involve stakeholders and planning of their activities in collaboration with ECPC
- June - September: Preparation and implementation of the awareness campaign

5.2 Fundraising – communications (toolkit)

Duration 1 year

Context

ECPC Members have different profiles from very small scaled organisations to nationally reputable federations. The diversity of their situation is reflected in their financing model and volume of resources available. Especially after the COVID-19 pandemic and its tremendous impact on the NGO and patient organization sphere, fundraising remains one of the main challenges ECPC members continue facing, therefore, we need to ensure that our members have all the available communications skills to ensure an increase in their available resources, so as to have an incremental impact on their work.

Objectives

- To support ECPC members to keep their independence from public and private funds diversifying the source of financing through providing them with campaign tools
- To sustain and to develop their activities through brainstorming via best practises that can be taught via trainings

Actions

- Elaboration of fact sheets and virtual trainings following the basic steps of a communications action plan, fundraising policy, strategy and project:
    - Crowdfunding: a combination of an on-site activity, together with online crowdfunding tools, such as GoFundMe or Facebook funding page

- Fundraising on-site event: an event that would happen in cooperation with our member organisations demonstrating the excessive need for funding, such as a conference in the European Parliament on World Cancer Day or another relevant day, charity sale, exhibition demonstrating art work from cancer patients, charity sale.

    - Donations and legacy

    - Legal obligations related to fundraising opportunities

    - Partnering with a private company and with other NGOs, either on an international or a European level, that have a tremendous impact on cancer patient advocacy

Timeframe / milestones

- Month 6-7: Writing and laying out fact sheets of 2023 and their promotion on ECPC's channels
- Month 8-10: Organising webinars and Communications training of ECPC's members organisations: June 2023, September 2023
- Month 6-12: Production of a toolkit on Communications as an outcome of the on best practices all year long

Deliverables

- Webinar report/s;
- Training of Member Organisations on improving their communications outreach;
- Updated Communications toolkit to be on top based on current data.

5.3 **Nutrition**

Duration: January 2023 – December 2023

Context

Nutrition is a crucial component of cancer treatment and rehabilitation as it helps patients cope better with illness. However, given the focus on the cancer and its cure, nutrition is often neglected, leaving patients and their families with doubts, questions and the need for practical guidance on how to eat better on a daily basis, especially during therapy. In 2015, ECPC sent out an extensive survey on nutrition and its importance in the treatment and life of cancer patients. The preliminary data obtained from the survey suggested that discrepancies existed between patients' expectations and the answers they may get from physicians about the metabolic and nutritional issues in cancer.

Building on the pilot survey, in 2016 ECPC continued its efforts with a second round of the survey in order to have enough data and maximise the impact of the answers received. The new version was adapted in order to directly

address individual cancer patients and cancer survivors. It aimed to describe and understand the perception of the importance of metabolic and nutritional problems among patients and cancer survivors. A total of 907 patients and survivors were surveyed in 10 European countries: Finland, Italy, Spain, Czech Republic, Greece, Denmark, Slovenia, Romania, Poland and Bulgaria. The study illustrated a substantial gap in terms of need for information and practical management of cancer-related nutritional problems for people with cancer.

With the Healthier Together - EU Non-Communicable Diseases (NCDs) Initiative, the European Commission aims to take action against the leading causes of avoidable premature death in Europe, building towards a strong European Health Union and complementing Europe's Beating Cancer Plan and the Farm to Fork Strategy. Addressing health determinants (alcohol and tobacco consumption, healthy diets and physical activity) will reduce the occurrence of personal risk factors in many people, such as high blood pressure, glucose intolerance and type 2 diabetes, overweight and obesity. This is an important topic to reach to the general population, including children, adolescents and vulnerable groups.

Objectives

At ECPC, we aim to raise health literacy on the importance of adopting a healthy diet and share useful information in collaboration with experts to support cancer patients make healthier choices during their treatment.

Actions

- Position Statement co-designed in collaboration with clinical experts and dieticians on the importance of nutrition during and beyond cancer treatment
- Awareness campaign - Patient stories on the importance of nutrition during and beyond cancer treatments
- Creation and dissemination of a nutrition toolkit (translation in many EU languages)
- Webinar in collaboration with experts

Timeframe / milestones

- Month 9-10 Position Statement
- Month 10-11 Awareness campaign - Patient stories dissemination activities
- Month 10-11 Dissemination of nutrition toolkit
- Month 12 Webinar on nutrition

Deliverables

- Position statement on nutrition
- Nutrition toolkit
- Webinars

5.4 LUNG-ember awareness campaign (NEW)

Duration: January 2023 - November 2023

Context

Globally, lung cancer has been the most common diagnosed cancer for the last several decades and the leading cause of cancer death globally. Early diagnosis of lung cancer can prolong survival for many years. Symptom burden when suffering from lung cancer places considerable physical and psychological distress on patients' well-being as both the disease-specific and treatment-induced symptoms could result in a series of impairments on patients' emotional status, social functions and quality of life. Smoking is one of the many causes for lung cancer and this has led to the misconception that lung cancer is a smokers disease. However, it is well documented that over half of those diagnosed are former smokers or people who have never smoked. it is important to highlight this as this misconception is linked to poor outcomes, due to delays in seeking treatment, disease-related distress, reduced social support and lower quality of care.

Objectives

At ECPC, we aim to develop a new campaign called LUNG-ember in order to increase awareness of the early screening importance, challenge the stigma associated with lung cancer, discuss new developments on ling cancer treatment and highlight the perspectives of people affected and their caregivers. The campaign will be launch in November (LUNG-ember) which is the Lung Cancer Awareness Month.

Actions

To achieve the objectives of this project the following activities will be carried out:

- Launch the LUNG-ember awareness campaign toolkit
- The development of support and awareness materials for patients and their caregivers
- Prepare videos with lung cancer patient storiesincluding the emotional journey into advanced/metastatic lung cancer in order to eliminate the stigma

Timeframe / milestones

- Month 2-6 Toolkit preparation
- Month 3-7 Development of support and awareness materials for patients and their caregivers
- Month 7-10 Production of the patient stories videos
- Month 11 Launch the campaign

Deliverables

- Report on the campaign results

5.5 EU Cancer Survivorship Day Campaign (NEW)

Duration: January 2023 - June 2023

Context

At present, there are around 20 million cancer survivors in the EU. Despite the rising number of cancer survivors, cancer survivorship can be a lifelong struggle.

Given the ad-hoc needs of cancer survivors and the persisting inequalities among EU countries, ECPC has started an initiative towards establishing an EU Cancer Survivorship Day by organising targeted events, such as "There is Life after Cancer: Putting an End to the Discrimination" (9 June 2020), "14 Million Reasons To Discuss Life After Cancer: Implementing The Right To Be Forgotten Across Europe" (19 February 2021) and "20 Million Reasons to Discuss Life after Cancer: establishing a European cancer survivorship day" (29 June 2021).

Cancer Survivorship Day is already being celebrated on the first Sunday of June in several countries all around the world, such as the USA, Canada, India, South Africa, and Australia.

The institutionalisation of an annual EU Cancer Survivorship Day will provide the EU with a unique opportunity to set up a dialogue with patients, their families and stakeholders, establishing a proper forum to discuss their specific needs and priorities to achieve a good quality of life after beating cancer, with an emphasis each year on a specific pattern of unmet needs.

Objectives

In 2021, ECPC and the Challenge Cancer Parliamentary Intergroup have started the process towards the establishment of an EU Cancer Survivorship Day as an opportunity to promote the scope of the European Beating Cancer Plan `and to support adequate policies to ensure rehabilitation and smooth reintegration of cancer survivors into social and professional life. In 2022, we sent letters to the European Commission and the EU Parliament to endorse the establishment of the annual EU Cancer Survivorship Day. In 2023, we will continue our endeavour in support of cancer survivors.

Actions

To achieve the above-mentioned objectives, ECPC will organise periodic meetings with the Challenge Cancer Intergroup Chair and Co-Chairs to align on the next steps towards the establishment of the EU Cancer Survivorship Day. Together, with the Intergroup, we will arrange meetings with the relevant people in the European Commission to discuss the approach to be taken in view of the institutionalisation of an annual EU Cancer Survivorship Day. We will also organise a multistakeholder targeted event in the European Parliament within the month of June to mark the EU Survivorship Day.

In support of this initiative, ECPC will also launch an online Survivorship Campaign within the month of June. This will take place via our social media channels, particularly Twitter, LinkedIn, Facebook and Instagram. The goal is to deliver key

messages to a wider audience, therefore, ECPC is planning to utilise all existing information streams. On the week of the campaign that includes:

- Drafting key messages for every social media channel;
- Preparing images to share together with the abovementioned messages and tailor them for the campaign purposes;
- Using the hashtag #eucancerssurvivorshipday in all our posts;
- Outreaching our Members and share with them our one pager with the key messages of the Survivorship Campaign to ensure they are aware of the campaign, plus request their input and ask for their participation;
- Post every day for more increased visibility.

Deliverables

- Posts for social media;
- One pager with key messages from the campaign to distribute among ECPC members;
- European Parliament event;
- Challenge Cancer Intergroup internal meetings.

Timeframe

- Months 1-2: Internal meetings with the Challenge Cancer Intergroup and the European Commission
- Months 3-4: Drafting of one pager and social media posts
- Months 3-4: Distributing the campaign material to our members
- Month 4-6: Awareness campaign on social media and European Parliament event

6. Strategic Alliances

Throughout the years ECPC has developed and consolidated several strategic partnerships as per the list below. With each of the following organisation, ECPC established a formal collaboration based on a framework contract or memorandum of understanding. During 2022 ECPC aims at strengthening even more those strategic alliances.

European Cancer Patient Coalition

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