



European Cancer
Patient Coalition



Action Plan 2021

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**European Cancer
Patient Coalition**

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Introduction

The voice of Europeans with cancer

The European Cancer Patient Coalition is the voice of people with cancer in Europe and beyond. With 450 members in 49 countries representing all EU Member States and Norway, Ukraine, Belarus, Switzerland, Bosnia and Herzegovina, Serbia, USA, Canada, Brasil, Peru, Nigeria, Russia, Israel, Turkey, Australia and New Zealand its vision is for a Europe of equality, where all Europeans with cancer have timely and affordable access to the best treatment and care available. ECPC works towards this vision by influencing the European political agenda, empowering and educating its members, and increasing the role of patients in cancer research.

The European Cancer Patient Coalition's 2020 achievements

2020 was a year of challenges for ECPC as well as the cancer community worldwide. The COVID19 pandemic has spread around the planet, sending billions of people into lockdown as health services struggle 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 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, ECPC has continued working to ensure that the rights of cancer patients are respected. We launched the survey "Mapping EU Member States' response to the COVID-19 pandemic and cancer". This was done to monitor the experience of cancer patients, cancer survivors and cancer carers across Europe. This survey was available in all EU languages.

Kathi Apostolidis served as President of ECPC until November. In December, Ken Mastris was elected as new President of ECPC. As he already stated, during his mandate he will be totally committed to promote patients' equality in cancer treatment and foster better quality of life for cancer patients and cancer survivors, in all of Europe. He will focus on working more closely with ECPC Members and stakeholders, as a multi-stakeholder approach is key to increase the quality of life of cancer patients in Europe and beyond.

ECPC continued its involvement in Working Parties and Committees of the European Medicines Agency (EMA), in TRANSCAN II, ECIBC-European Commission Initiative for Breast Cancer, Innovative Partnership for Action Against Cancer (iPAAC) and on the EURACAN - European Reference Networks (ERNs).

Work on other European Union funded projects continued, including 10 Horizon 2020 projects (DIAdIC, EUCANCan, HTx, ImmunoSABR, LEGACy, PalliativeSedation, TRANSCAN-2, LifeChamps, QUALITOP, Instand-NGS4P), 3 Innovative Medicine Initiative (IMI) projects (BD4BO PIONEER, Immune-Image, PREFER), 2 Innovative Training Networks (ITN) (ELBA and PREDICT). Over 20 new project proposals were submitted, and 4 new projects were approved by the European Commission with ECPC as a relevant partner representing the patient voice. A new project was funded by a private foundation on mapping and promoting the “Right to be Forgotten”, building on the success of the relevant laws in France and Belgium.

Furthermore, coinciding with World Cancer Day and the Commission’s launch of the consultation period for Europe’s Beating Cancer Plan, the European Parliament confirmed the establishment of a first Parliamentary Intergroup dealing exclusively with cancer which was officially launched in July 2020 and is named “Challenge cancer”. The kick-off meeting of the Intergroup took place in October 2020 and the first online webinar organised by the Intergroup focused on “The Cancer Momentum: Fighting Inequalities in Europe”.

This first and only EU Parliamentary Intergroup on cancer serves as a forum for MEPs from all political parties to engage in dialogue with patients, cancer survivors and 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. ECPC is managing the secretariat of the “Challenge Cancer” Parliamentary Intergroup.

Innovative approaches to cancer treatment, diagnostic methods, introduction of big data and artificial intelligence to the diagnosis, treatment and prognosis of cancer, are at the centre of most new project proposals. ECPC follows closely the development in these fields and remains protagonist as expressing the patient voice on them e.g., personalised medicine, immunotherapy, biologic and biosimilar medicines, as well as new cancer diagnostics, including new biomarker tests, NGS-New Generation Sequencing and WGS – Whole Genome Sequencing. ECPC has started two new projects in 2020 one on cancer related complications and comorbidities and one on a Chimeric Antigen Receptor (CAR) T-cells for certain types of blood cancers.

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 the Cancer Mission and the Europe’s Beating Cancer Plan.

As research comes 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 will act as the missing link between all the relevant stakeholders, always keeping in mind patient centricity, ethics and sustainability. ECPC, based on its unique expertise and perspective, is the bridge between research and healthcare and works effectively with both. With this purpose in mind, ECPC will continue to engage with the oncology community and European Institutions on the principle of “Science with and for Society”.

ECPC collaborated closely with its Members across Europe on several awareness-raising campaigns, including bladder cancer, rare cancers, head and neck cancer, physical activity and nutrition, Merkel Cell Carcinoma, non melanoma skin cancers and personalised medicine. 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 Member is essential for the work of the organisation.

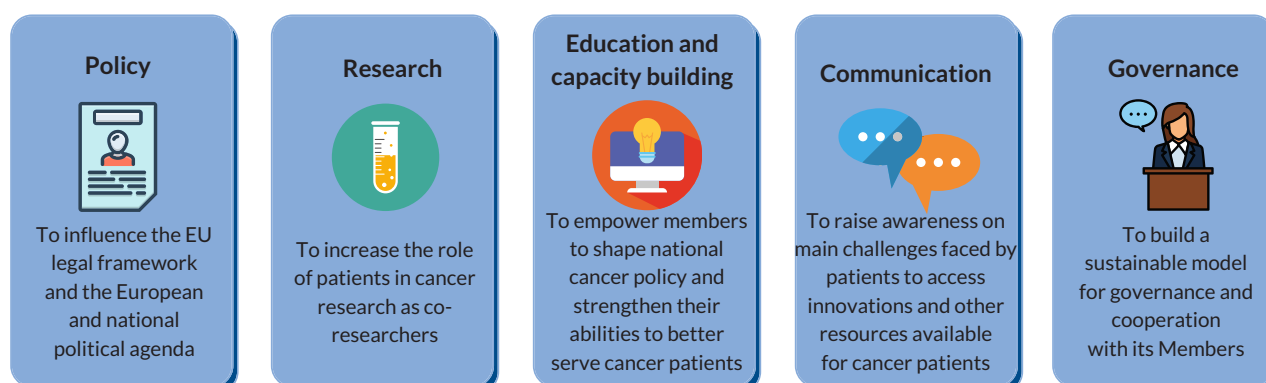
ECPC's contribution to cancer research and care has been further recognised by having ECPC representatives invited to Boards and Committees of top-level European cancer organisations, such as European Academy of Cancer Sciences-EACS, Cancer Core Europe-CCE, Cancer Drug Development Forum CDDF, Pancreatic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

The European Cancer Patient Coalition Strategy

The European Cancer Patient Coalition Board's 2019-2022 strategy is based upon five pillars:

- Policy: influence the EU legal framework and the European and national political agenda
- Research: increase the role of patients in cancer research as co-researchers
- Education, such as capacity building: empower members to shape national cancer policy and strengthen their abilities to better serve cancer patients
- Communication: raise awareness on main challenges faced by cancer patients and families to access innovations and other resources available for cancer patients and carers
- Governance: build a sustainable model for governance and cooperation with its Members.

The European Cancer Patient Coalition Board's 2019-2022 strategy is based upon five pillars:



1. The European Cancer Patient Coalition Objectives

The main objectives of the 2021 Action Plan are to further support and advocate for cancer patient rights, to develop a strong engagement with the European Institutions members, to strengthen 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 remain to be the voice of people with cancer in Europe. To do so, ECPC will continue to follow and contribute to a variety of policy issues at the European level, based on our Action Plan and Strategy and to follow and intervene in, where appropriate, the main EU health, research, and other relevant policy topics. In 2021, the European Cancer Patient Coalition will focus on developing the following main policy themes:

- Health technology assessment
- Rare cancers
- Survivorship care
- Right to be Forgotten
- Social disparities and health inequalities in Europe
- Supporting cancer carers in Europe
- Personalised medicine
- Cancer Mission Europe
- Cancer Comorbidities
- Big data and digital health
- Innovative treatments e.g., CAR T Cell, and new approaches
- Efficiency and sustainability

1.2 Health and Research

Participation and partnering in cancer research projects allow ECPC to be at the forefront of scientific developments. ECPC works to ensure that the patient perspective is not only heard and respected but also integrated in

the research deliverables while improving scientific knowledge about cancer. 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 2021 health and research objective is to integrate Members into scientific projects and broadly disseminate project results using a language and format accessible to ordinary patients.

In 2021, ECPC will continue to contribute to on-going European research projects, as well as to join consortia to bid on new project proposals. ECPC is currently involved in the Innovative Partnership for Action Against Cancer (iPAAC), the ECIBC-European Commission Initiative for Breast Cancer, 9 Horizon 2020 projects (DIAdIC, EUCANCan, HTx, ImmunoSABR, LEGACy, PalliativeSedation, LifeChamps, QUALITOP, Instand-NGS4P), 3 Innovative Medicine Initiative (IMI) projects (BD4BO PIONEER, Immune-Image, PREFER) and 2 Innovative Training Networks (ITN) (ELBA and PREDICT). In 2020, the European Cancer Patient Coalition began work on its first project funded by the European Institute of Innovation and Technology (EIT) Health, "Empowering European Patients in Radiation Oncology" (E-PRO). In 2021 ECPC will also be kicking off 2 additional projects T2EVOLVE and INTERVENE.

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. ECPC renewed its contacts with old and new members, despite, due to COVID-19 restrictions, in 2020 we could not meet them at our Annual General Meeting that was held virtually in November. 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, 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 2021 education and capacity building objectives are to increase and continue the dialogue between the Coalition and its Members to ensure increased capacity for both. The Membership and Communications Team will work closely with the Board, to set up a communication strategy to better interact with Members and boost our collaboration with internal and external stakeholders. ECPC will encourage Members to be involved with existing Working Groups (Rare Cancers, Urological cancers and Social Disparities), recognising their value to tackle important issues in cancer and invite them to create new ones.

1.4 Communication and Awareness Raising

In 2021, an important objective will be to implement a communication strategy and an annual communications plan. This will address communication towards our members, press relations, social media activity, and support to the Policy work and Health and Research projects, while ensuring sufficient flexibility to adapt to unplanned strategic communications.

The work on the new website was consolidated in 2020 and in 2021 we will continue working on its update, daily maintenance and implementation with new features as we develop new projects.

Awareness campaigns on head and neck cancer, prostate cancer, personalised medicine, nutrition and physical activity, bladder cancer, non melanoma skin cancer will continue in 2021, while new ones will be added. Throughout this year we have also supported several campaigns of our partners and members and we will continue to do so throughout 2021.

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 Toxic Neuropathy Consortium (TNC), the European Society for Medical Oncology (ESMO), the Cancer Drug Development Forum (CDDF), European Alliance for Personalised Medicine, Worldwide innovative networking in personalised cancer medicine (WIN), European Academy of Cancer Science (EACS), The European Nutrition for Health Alliance, Federation of European Academies of Medicine (FEAM), Union for International Cancer Control (UICC), Organisation of European Cancer Institutes (OEI), Cancer Core Europe, European Organisation for Research and Treatment of Cancer (EORTC), European Association of Urology (EAU), European Cancer Concord (ECC), European Medicines Agency (EMA), European Cancer Organisation (ECO) contributing to a compelling pack of joint initiatives.

In relation to strategic alliances, the objective for 2021 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.

1.6 How to read the Action Plan 2021

ECPC action plan outlines the main proposed activities for 2021. The activities are divided into:

- Policy and Advocacy projects related directly to the ECPC mission to represent Europeans with cancer and to advocate on key policy issues affecting people with cancer

- EU funded projects that allow ECPC to be at the forefront of scientific developments on cancer, providing the patients perspective in European cancer research
- Education & Capacity building activities aimed at providing Members with the tools to advocate for policy change at national level, with new instruments to help people with cancer, and with educational projects designed to educate people with cancer and patient organisations about issues that are important to them
- Communication and awareness raising activities including campaigns to empower our Members, cancer patients and the public
- Strategic Alliances with other organisations, including European institutions, scientific societies and academia that increase the Coalition's capacity to serve the needs of its Members. ECPC counts on the direct, experienced and voluntary support of the Board and Members in the development and implementation of all activities of the Action Plan.

2. Policy and Advocacy

2.1 Health Technology Assessment-(HTA)

Duration: January 2021 – December 2021

Context

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.

ECPC highlighted the severity of delays in the 2015 report **“Challenging the Europe of Disparities in Cancer”**, where access to life-saving cancer medicines was delayed for years mainly due to differences in Pricing & Reimbursement methodologies and HTA evaluations. The existing approach of parallel assessments by HTA bodies in every EU Member State, using different methodologies based on a common evidence base 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 EC set out a proposal for a regulation for future EU cooperation on HTA. The proposal focusses 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. This framework is the Joint Clinical Assessments (JCAs), which paired with non-clinical assessment (such as cost and economic evaluation, ethical analysis, organisational and legal aspects, patient and social aspects, including quality of life) would inform the real value of medicine for Pricing & Reimbursement (P&R) at Member State level. The European Parliament has already unanimously approved its negotiation position in February 2019 for inter-institutional negotiations with the Council and Member States, and strongly supports the EU JCAs. The ultimate goal is greater harmonisation of Pricing & Reimbursement and speeding up of JCAs, providing a pan-European indication of the real value of innovative medicines.

Early 2019, ECPC launched an online educational module for cancer patients on HTA, which helped to increase knowledge and confidence for ECPC members to participate in HTA bodies at national level, advocate for it where there are no established frameworks for patient involvement in HTA. To further increase the impact of the HTA e-module, country-based workshops were organised in Poland, Greece, Portugal and Spain. Within 2020, ECPC developed a toolkit for

patients and patient organizations on how cancer patients can be involved in the HTA process. The toolkit is country specific, as it has a sort of step-by-step guide for cancer patients to follow in order to be an active part of the HTA process in the respective country. As HTA processes vary within EU countries, 2020 edition focused on Spain and Portugal and provided information with regards to each Country's HTA system, the National and Regional HTA Agencies and what is the process for individual patients in order to be involved in a patient organization of their country.

The challenge though still remains with Member States. Up to now, what is established in the proposed EU regulation was not welcomed by all Member States, several of which have expressed strong reservations in the mandatory uptake of the JCA reports. ECPC will continue to monitor closely the progress in 2021.

Objectives

As Member States continue to work in the Council of the EU to reach an agreement on the JCAs uptake, there is an immediate need for stronger, enabled and empowered patient organisations at a national level, where non-clinical domains are assessed such as patient and social aspects, as well as ethical analysis, legal aspects and cost and economic evaluation.

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 country-based 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

- ECPC will translate and adapt the toolkit in at least 2 EU countries and languages and add country specific information.
- Raise awareness and Build on the HTA workshops in 2 additional EU countries. ECPC will organise online workshops for patient organisations at a national level and a broader workshop at the ECPC Annual Congress 2021.

- ECPC will organize HTA trainings to activate member patient organisations, to prepare them with more detailed guidance on patient involvement in HTA in their countries and seek input from members in countries where patient involvement in HTA is more advanced.

Deliverables

- Updated and tailored version of the toolkit for two additional countries
- Translations of the toolkit
- Workshop at the ECPC Annual Congress 2021
- 2 National workshops in partnership with ECPC Members
- Training sessions for ECPC Members with detailed information on patient involvement in HTA bodies in the different Member States.

Timeframe

Month 1-6 Update, adaptation and translation of the toolkit

Month 1-6 Organisation of National Workshops

Month 1-9 Organization of HTA trainings for activate member patient organisations

Month 3-6 Organisation of the workshop at ECPC annual congress in June 2021

2.2 Personalised Medicine

Duration: January 2021 – December 2021

Context

Each year, over 3 million people are diagnosed with cancer in Europe. During the 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 individualized, 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. 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. This needs to change as it further creates 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 (See ECPC last campaign here: <http://www.ecpc.org/edu/personalisedmedicine>) to put personalised medicine for cancer prevention, diagnosis, prognosis and therapy into the spotlight of the European and national agenda.

In 2018, ECPC held an event in Brussels in collaboration with the Cancer Drug Development Forum (CDDF) and has launched the first-ever 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. ECPC continued the pan-European campaign in 2019 and 2020 and also the collaboration with the European Alliance for Personalised Medicine (EAPM). In 2020 ECPC collaborated with the International Quality Network for Pathology (IQN-Path) to implement a survey among cancer patients to understand the gaps in knowledge and accessibility to biomarker testing across Europe. The results of the survey will be launched early in 2021.

As the awareness of health care providers in Europe about cancer molecular testing remains low (23%), ECPC through its involvement in the Innovative Partnership on Action Against Cancer (iPAAC), will contribute to raise awareness.

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 2021 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
- Launch with IQN-Path the results of the survey conducted in 2020 to better understand the situation in the Member States on quality of biomarker testing and access in Europe
- 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
- 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
- Supporting a resolution to the European Parliament calling on the constant efforts and establishment of a wider coherence and the development of a Directive for personalised treatment for cancer prevention, diagnosis, prognosis and therapy and adaptation of the Directive from all Member States.

Deliverables:

- Pan-European Awareness Campaign
- Campaign toolkit for ECPC member patient organisations, healthcare professionals and patients to run campaigns at national level
- Translation of the toolkit in selected languages (n. to be identified and depending on funding available)
- Dissemination of the booklet and its translation in several EU languages (n. of languages depending on funding available)
- European Parliament resolution
- Videos and online material of the social media campaign

Timeframe:

Month 1-11: Planning and organisation of the personalised Medicine awareness campaign

Month 2-6: Translation of the booklet into several EU languages

Month 5-11: Dissemination of the booklet

Month 1-3: Organization and planning of the European Parliament event

Month 2-10: Update of the report on the quality of biomarker testing and access in Europe with ESMO

Month 2-11: Preparation of the European Parliament resolution

Month 11: Publish the European Parliament resolution

2.3 Right to be forgotten

Duration: January 2021 – December 2021

Context

The proportion of cancer survivors is increasing of 3% on a yearly basis and in 2020 around 14 million cancer survivors have been estimated in Europe.

Once the cure of cancer is declared, patients should be back to their lives, as other people of similar age and socio-demographic characteristics with no cancer diagnosis. However, returning to life in society can be challenging for several reasons. Survivors of cancer across Europe are experiencing several obstacles, in particular when looking for access to financial services, such as mortgages and insurances.

In this respect, the EU Member States as France, Belgium, Luxembourg and the Netherlands implemented the Right to be forgotten for cancer survivors in their national legal systems¹.

These national initiatives have a lot of communalities and largely implement the same principles, allowing cancer survivors to contract life insurances or other financial instruments such as mortgages and loans, and launch new professional projects without fear of their cancer being used against them.

These initiatives ensure access to financial instruments to former cancer patients 10 years after the end of their treatment provided that no relapse occurred. In some countries, this term is reduced to 5 years in the case of paediatric cancers.

Moreover, these national measures include relevant derogations for a number of cancers with a better prognosis. This list is regularly updated and ensures reduced terms to enjoy the Right to be Forgotten for cancer survivors.

For former patients, financial discrimination remains a true obstacle with serious negative impact on appropriate quality of life, equality and social inclusion.

In this respect, an important step forward was the inclusion of the Right to Be Forgotten as a measure of best practice to ensure the best possible quality of life for cancer survivors in the roadmap for the EU Beating Cancer Plan, promoted by the EU Commission in February 2020 ([European Commission, 2020](#)). Lately, the Interim Report of the Mission Board for Cancer included the Right to be forgotten among the recommendations to the EU Member States to counteract discrimination and to ensure equality ([Directorate-General for Research and Innovation \[European Commission\], 2020](#)).

In 2020, ECPC started a new project on the Right to Be Forgotten under the supervision of Dr Françoise Meunier. The aim of the initiative is to conduct a legal research project assessing and monitoring the discrimination that cancer survivors face in attempts to obtain a mortgage, loans and life insurances, and other financial services.

¹ For more information please visit Factsheet on the Right to be forgotten in the EU National Legislations Legal Background and current status from France, Belgium, Luxembourg and the Netherlands.

The current research extends to all EU Member States, with the aim of raising awareness, but above all assessing the conditions for a common European regulatory proposal recognising the right to be forgotten for EU citizens.

The goal of the project is to enable the ECPC to map the current situation in depth in each of the EU Member States, to raise awareness and identify the actions that can be put in place at EU level.

Objectives

The “Right to be Forgotten” project aims to enable ECPC to build a strong evidence base to actively drive advocacy to enhance policy measures with European institutions and Member States’ governments to end discriminatory practices in financial services faced by cancer survivors in Europe.

Actions

To achieve this, we plan to further assess the long-term impact of the national legal frameworks having implemented the “Right to be Forgotten” on cancer survivors’ quality of life, reintegration to socio-economic life, socio-economic impact on financial services, employment and national social protection budgets.

The results will then be used to identify the actions that can be put in place at EU level. The project will also map the current situation in depth in each of the EU Member States. The collected data will enable strong advocacy with EU institutions and MSs governments to showcase the effectiveness of the existing laws to date. The results of the collected data and analysis will encourage a wider debate about the social needs of cancer survivors, highlighting the necessity to provide them a specific status in the national and EU policies, with appropriate prerogatives of which the right to be forgotten is an integral part.

This debate will be initiated with a European parliament event where the content of the legislative initiatives implemented will be presented and disseminated among several relevant stakeholders to promote all successful practices to avoid the risk of discrimination for cancer survivors. A toolkit to create strong evidence-based and effective advocacy for the introduction of “Right to be Forgotten” legislations across the EU through fact sheets, scientific articles, policy and white papers and recommendations will be created.

Finally, ECPC will facilitate evidence-based advocacy with national governments and the European Commission to drive the implementation of “Right to be Forgotten” laws in all EU Member States for ECPC member patient organisations ad hoc meetings with relevant policy makers and stakeholders.

Deliverables

- Updated report on the impact and level of implementation of the “Right to be Forgotten” laws
- Right to be Forgotten Toolkit
- EU parliament event
- Ad hoc meetings with relevant policy makers and stakeholders

Timeframe

- Month 1-4 Data collection, analysis and update of the information on the impact and the level of implementation of the “Right to be Forgotten” laws, First EU parliament event
- Month 3-5 Right to be Forgotten Toolkit
- Month 6-9 (2nd) EU parliament event
- Month 6-12 Ad hoc meetings with relevant policy makers and stakeholders

2.4 CAR-T Treatments

Duration: January 2021 – December 2021

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 order to ensure patient access and realise the full potential of CAR Ts for patients, a multi- stakeholder collaboration at pan-European level - bringing together patients, industry, CAR T experts (oncologists, haematologists, cell transplants) and others - is needed to identify and discuss challenges and potential policy solutions regarding, for example:

- Cross border challenges
- Regulatory approval
- Complementarity and differences between commercial and non-commercial CAR T

- Manufacture, quality control, distribution (including the scalability of these processes)
- Toxicity risk management
- Real-world data collection (e.g. registries) and value assessment
- Reimbursement

A concrete outcome of this multi-stakeholder collaboration will be 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.

ECPC as the patient voice for cancer patients in Europe must be involve and will empower its members and raise their awareness through the dissemination of fact sheets and the organisations of webinars on the positive outcomes of CAR Ts to patients.

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. With two treatments already approved for blood cancers, a third in the pipeline and new clinical studies examining the possibilities of CAR T with solid tumours, 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 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:

- Convene a platform of patients and caregivers, clinicians, industry representatives, geneticists, pharma industry, payers and other experts and stakeholders to delineate the access problems from the patient perspective
- Conduct a literature review to gather all the updated information and

use these data to feed the White Paper, the platform procedures and the awareness material.

- Publish a White Paper aiming to inform cancer patients, other relevant European and national stakeholders including EU Policy makers about CAR T available treatments, research in this area and policy challenges
- Translate the White Paper into selected languages (n. of languages to be defined)
- Publish a fact sheet and translate it in selected languages (n. of languages to be defined)
- Organize an online event at the EU Parliament co-hosted by the Challenge Cancer Parliamentary Intergroup to present the White Paper, 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.

Deliverables

- Stakeholders Platform
- Literature review on CAR T cells
- a White Paper on CAR T cells with recommendations for policy makers and a call to action
- Translated version of the White paper
- Awareness material
- Translated version of the material
- Online event at the EU Parliament to present the White Paper
- Activity Plan for the following year for ad hoc countries

Timeframe

Month 1–12 Implementation of the CAR T Platform and constant increase of outreach and membership

Month 1-4 Identification and agreement among all the members of a Mission Statement for the Platform

Month 3-8 Conduction of the literature review

Month 8-11 Elaboration of a White Paper with recommendations and a call to action

Month 8-9 Elaboration of a fact sheet

Month 11 Launch of the White Paper with an event at the EU Parliament

Month 11-12 Translation of the White Paper and fact sheet

2.5 Cancer comorbidities

Duration: January 2021 – December 2021

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. The Europe's Beating Cancer Plan sets the agenda of the new Commission and of the Parliament. Cancer is set to become a top health priority for the next five years in the EU, with both the European Commission President, Ursula von der Leyen, and Commissioner for Health and Food Safety, Stella Kyriakides, having made clear that cancer will play a central role in their policy agenda and that the output will be the Europe's Beating Cancer Plan.

It is time to increase the attention given to cancer patients' long-term well-being 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.

In addition, Horizon Europe, the EU's €100 billion research and innovation programme for 2021-2027 includes a specific mission on cancer; its content and outputs are still under development. Furthermore, the main EU initiative on cancer during the last mandate, CanCon, made several recommendations in its [guide](#) (2017) directly linked to cancer-related complications and comorbidities. These include setting up Multidisciplinary Comprehensive Cancer Care Networks (CCCNs) to ensure that the management of patients with comorbidities be shared with relevant specialists; putting in place a defined pathway on integrated cancer control, including psychosocial support and careful use of complementary medicines being used; and setting up a data collection system to look into, among other things, the impact and management of comorbidities. The actions from CanCon are now addressed by the Innovative Partnership for Action Against Cancer (iPAAC) Joint Action, under the leadership of the German Ministry of Health and the German Cancer Society. iPAAC was launched in 2018 and aimed to build upon the outcomes of previous Joint Actions. A Roadmap on Implementation and Sustainability of Cancer Control Actions was the main deliverable of this Joint Action in April 2020. The Commission is also supporting a Joint Action on the implementation of digitally enabled integrated person-centred care, which will be led by Member States.

The idea for this initiative on cancer-related complications and comorbidities came up after the European Cancer Patient Coalition (ECPC) and the European

Thrombosis and Haemostasis Alliance (ETHA) organised some events and projects on cancer associated thrombosis. The experience of these projects highlighted that the broader challenge of cancer-related complications and comorbidities requires further policy attention.

Objectives

Given the current context, the purpose of this initiative is to amplify each organisation's voice 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 24 members:

1. European Cancer Patient Coalition (ECPC) - CHAIR

2. European Association for the Study of Obesity (EASO)
3. European Association of Urology (EAU)
4. European Brain Council (EBC)
5. European Cancer Organization (ECO)
6. Eurocarers
7. The European Federation of the Associations of Dietitians (EFAD)
8. European Federation of Neurological Associations (EFNA)
9. European Geriatric Medicine Society (EuGMS)
10. European Nutrition for Health Alliance (ENHA)
11. European Pain Federation (EFIC)
12. European Society of Surgical Oncology (ESSO)
13. European Society of Cardiology (ESC)
14. European Specialist Nurses Organisation (ESNO)

15. European Thrombosis and Haemostasis Alliance (ETHA)
16. International Society on Thrombosis and Hemostasis (ISTH)
17. International Society of Geriatric Oncology (SIOG)
18. Thrombosis Ireland
19. Thrombosis UK
20. University KU Leuven (KU)
21. Leuven Cancer Institute (LKI)
22. International Psycho-Oncology Society (IPOS)
23. The European Society for Clinical Nutrition and Metabolism (ESPEN)
24. 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.

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. It has also been used for the open consultations on the Europe's Beating cancer Plan and the Cancer Mission.
- **White Paper on cancer comorbidities:** based on the comprehensive literature review developed in 2020, a White Paper on Cancer Comorbidities and Complications aiming to further communicate this issue at EU policy level and by individual organizations in their own activities. The White Paper is to be released in January 2021.
- **Infographics and other visual materials:** to facilitate an impactful communication with Policy Makers and other relevant stakeholders, we will explore ways of making our message more engaging, such as by creating infographics.
- **Direct engagement:** Cancer champions: influential cancer champions will be identified within the Parliamentary Intergroup Challenge
- **Event at the EU Parliament:** An event at the EU Parliament will be organised to sensitize MEPs on the issue and put forward the call to action. It will be co-hosted by the Parliamentary Intergroup Challenge Cancer in Q1 of 2021.

Deliverables

- White Paper on Cancer Comorbidities and complications
- Strategic plan for the year 2021

- Follow up meetings with relevant stakeholders
- A high-level meeting at the European Parliament
- A social media campaign on Cancer comorbidities and complications

Timeframe

- Month 1-12 Organization of follow up meetings with relevant stakeholders, such as the European Commission for the Beating Cancer Plan, the Cancer Mission Board Chair, Challenge Cancer and MAC and other interested MEPs, such as the BECA group.
- Month 1-8: Dissemination of the White Paper on Cancer Comorbidities and complications
- Month 1-2: Convene a strategy planning meeting to identify the best strategy for the year and set up implementing actions
- Month 1-4: Organisation of a high-level meeting at the European Parliament
- Month 1-6: Organisation of a social media campaign on Cancer comorbidities and complications.

2.6 Challenge Cancer Intergroup

Duration: January 2021 – December 2021

Context

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



The Intergroup was conceived by ECPC to ensure continuity in the European Parliament's work on cancer during the previous and the current mandates. The Intergroup will serve 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 will act 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 450 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 will enable 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 will strive 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 2021 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 activities of the Intergroup
- Supporting EU measures and a resolution of the European Parliament, adapted for all Member States, on **personalised treatment** for cancer prevention, diagnosis, prognosis and therapy
- 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**)
- Advocating with the **Cancer Mission** Board and MEPs that are members of the Intergroup on concerns related to cancer patients, survivors and carers
- Building on the **White Paper on Social Disparities** in Europe, ECPC will organise debates within the Intergroup to find ways to facilitate policy

changes in social and employment laws across individual Member States and to support the implementation of these changes into national cancer plans

- 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 a 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 and that the Cross-Border Healthcare Directive is functional and its provisions accessible in the interest of rare cancer patients
- 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**
- Raising awareness on the cancer patients' high risk of healthcare-associated infections and work with MEPs to ensure that this aspect will be addressed in the long-awaited legislative proposal by the European Commission on **antimicrobial resistance** (AMR)
- 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
- Raising awareness on rare cancers, such as **Pancreatic Cancer and Merkel Cell Carcinoma** and on a number of cancers, such as **Bladder, Non Melanoma Skin Cancer and Breast Cancer**, which have a high social and economic impact
- Engaging with MEPs and experts to drive concrete policy recommendations stemming from policy discussion within the Challenge Cancer Intergroup

Deliverables:

- Informative webinars for MEPs, their assistants and their policy advisors on cancer-related priorities

- European Parliament resolutions (n. to be identified)
- Web hub where stakeholders can follow the agenda and the activities of the Intergroup
- 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

Timeframe:

- **Months 1-12:** Members of the Intergroup will be involved and supported in internal and external meetings and events
- **Months 1-3:** Creation of a web hub where stakeholders can follow the agenda and the activities of the Intergroup
- **Month 1:** Webinar on the EU Joint Action on Rare Cancers (JARC) recommendations for the Rare Cancer Agenda 2030
- **Month 2:** Event on the World Cancer Day
- **Month 3:** Webinar on nutrition and physical activity in cancer
- **Month 6:** Webinar on the non-melanoma skin cancer and on the Right to be Forgotten (International Survivorship Day)
- **Month 9:** Webinar on head and neck cancer
- **Month 11:** Webinar on personalised medicine
- **Months 6-12:** The MEP members of the Intergroup will draft resolutions

2.7 Covid19

Duration: January 2021 – December 2021

Context

Coronavirus has spread around the planet, sending billions of people into lockdown as health services struggle to cope. As this disease can endanger cancer patients directly or indirectly, ECPC is committed to provide its members and the larger cancer community with the most current information to ensure the cancer patients are safe and protected during the pandemic.

The causes of COVID-19–related deaths are not clearly defined in the international reports available so far, but data from Italy, where +20% of all COVID-19 mortality was among cancer patients, amplify the importance of the #StayHome request of national health authorities. This confirms the WHO indication 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.

ECPC has set up a Web Hub accessible from the home page of the website. Please, see the following link <https://ecpc.org/covid-19-information/> which is constantly updated.

The pressing question that cancer patients and survivors face is whether they are at increased risk. ECPC have 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).

Co-infections of the upper airways may increase the risk of an adverse outcome in patients with viral infections; especially, co-infections caused by bacteria and fungi have a significant impact on the outcome of the primary viral infection. Chronic inflammatory and obstructive pulmonary disease can increase the risk of major respiratory complications.

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.

Objectives

ECPC strives to inform its member organisations by continuously updating the dedicated COVID-19 hub (<https://ecpc.org/covid-19-information/>) on the ECPC website.

This currently includes the following areas:

- COVID-19 Information

- Guidelines on COVID-19 for cancer patients in Arabic, Bulgarian, Catalan, Chinese, Croatian, Czech, Dutch, English, French, German, Greek, Hungarian, Italian, Japanese, Norwegian, Polish, Portuguese, Romanian, Russian, Serbian, Slovenian, Spanish, Swedish, Urdu
- Urgent requests for support from ECPC members
- Opportunities for funding
- Our members responses
- Resources

With additional funding the web hub will be implemented with the following:

- Continues updates and translations of the guidelines
- Development of factsheets
- Possible psychological support to cancer patients at the time of COVID-19 and during the vaccination period, depending on funding available
- Continues support and monitor any irregularities in terms of treatment and vaccination for cancer patients during 2021.
- Support Cancer Patients based on the need identified through the survey conducted during 2020

Actions

- Update of the COVID-19 hub
- Publish, update and translate the COVID-19 statement and guidelines for cancer patients
- Survey on COVID-19 and cancer patients to better understand the consequences of covid 19 during 2021. ECPC will conduct a second wave of its survey on how the Member States responded to the pandemic in relation to cancer patients. We aim also to investigate the impact of the pandemic to cancer patients caregivers around Europe and the impact of the vaccination, any obstacles, procedure or availability issues and side-effects will be investigated.
- The results will be available on the ECPC website and shared through social media (through clear messages such as infographics) and will serve as a basis for an open letter or press release.
- Publication of the survey results into a peer-reviewed indexed scientific journal
- Social media campaign spanning the COVID-19 epidemic and informing the general public and policy makers on the challenges cancer patients are going through
- COVID-19 Follow up with a publication on lessons learned and recommendations for policy makers

- Organisation of webinars to inform and empower cancer patients
- Collection of patient stories highlighting the challenges faced with COVID-19. These are to be shared on the ECPC website and further disseminated through social media together with interviews with healthcare professionals, epidemiologists and cancer patients.

Deliverables

- Updated COVID-19 hub on the ECPC website
- Updated guidelines and new translations
- COVID-19 psycho-social support recommendations and factsheet
- A series of COVID-19 webinars for cancer patients
- Translated COVID-19 statement
- Open letter or press release based on the survey
- Survey results publication
- Patients stories and additional interviews
- COVID-19 media strategy
- Policy paper with recommendations as a COVID-19 follow up

Timeframe

- Month 1: Media strategy update of COVID-19 hub and COVID-19 statement
- Month 1- 12: Guidelines translations- updates, Statement translations- updates, patient stories, interviews
- Month 2-6: Webinars, recommendations, COVID-19 psycho-social support recommendations and factsheet, policy paper with recommendations as a COVID-19 follow up, Patients stories and additional interviews
- Month 4-10: COVID-19 survey for cancer patients and caregivers
- Month 11-12: Submission of the survey results for publication

2.8 Immuno-Oncology Portal Update

Duration: January 2021 – December 2021

Context

Immuno-oncology therapies offer significant potential for a growing number of patients with many forms of cancer. Using the body's own immune system to fight disease, immuno-oncology has transformed the prognosis for many types of cancer. Our understanding of how these therapies work is evolving rapidly

as more immuno-oncology therapies become available. It is important that regulatory and policy landscapes anticipate the innovation in immuno-oncology, in order to reduce barriers to cancer patients' access and avoid further increases in inequalities across Europe. Simultaneously, it is essential that we provide patients with accurate, up-to-date information to help them have a meaningful dialogue with their doctors about the role that these therapies may play in their treatment.

The Immuno-oncology Portal (IOP) was created in 2015 to provide up-to-date and accessible information about cancer immunotherapies to inform patients, healthcare providers, policymakers, and stakeholders about the promises of immunotherapies guided by two principles: Patient-centeredness and scientific accuracy.

The field of cancer immunology is growing and changing rapidly as is the number of possible treatments. Some cancers like advanced melanoma that previously was considered untreatable can in some instances now be treated by immunotherapies. As a contrast to the promising outlook these new therapies bring to cancer patients however, it is very difficult to find easily accessible and understandable information about them.

Objectives

The portal aims to empower patients and caregivers providing information in a simple and understandable way. All the information on the portal is scientifically accurate and is continuously updated to reflect the newest advances in immuno-oncology. The IOP is divided into two main sections: The first provides an introduction to cancer immunology while the second provides a comprehensive list of the availability and reimbursement of immunotherapies across Europe.

Actions

ECPC will build on the work of the previous years to update the content of the portal in both sections. A working group will be set to update the content

Deliverables

- Working Group to update the content of the portal
- Updated portal information

Timeframe

Month 1-3: Establishment of the Working group

Month 2-12: Update of the portal information in both sections

2.9 Non-melanoma skin cancer

Duration: January 2021 – December 2021

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.

For these reasons, actions and measures are required at European level in order to promote early screening and detection of skin malignancies as well as to increase awareness and protection of outdoor workers.

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.

With the European Commission set to present its milestone strategy on cancer, Europe's Beating Cancer Plan by the end of 2020, ECPC conducted a literature review and produced two awareness factsheets (one for 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 12th October, 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 brought together more than 30 participants from across the world, representing patient advocacy groups, workers unions, occupational safety and health professionals, social security representatives, dermatologists, and oncologists. 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 official recognizing NMSC as an occupational diseases. A representative of the European Commission's team working on Europe's Beating Cancer Plan (EBCP), and two Members of the European Parliament sitting on the Parliament's Special Committee on Beating Cancer (BECA) also took part.

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

Actions

ECPC will build on the past year's developments to update and conduct the "Facing the Sun" social media campaign by producing a new toolkit with material

such as videos, factsheets and other material. The toolkit will be available for ECPC member organizations to use at national level. In addition, ECPC will join forces with EADV to organize a workshop 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 such as outdoor workers from UVR. Finally, ECPC, will organize ad hoc meetings with Members of the EU Parliament and the Challenge Cancer Intergroup.

Deliverables

- Toolkit for social media campaign
- Report of the workshop/webinar

Timeframe

Month 1-4: Production of the Toolkit for social media campaign material

Month 5-6: "Facing the Sun" social media campaign implementation

Month 5-6: ECPC - EADV joint workshop

Month 4-12: ad hoc meetings with Members of the EU Parliament and the Challenge Cancer Intergroup

2.10 Digital health

Duration: January 2021 – December 2021

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.

Former president of the European Commission, Mr. Andrus Ansip, wrote in his blog that "Digital Technology can help to increase efficiency, bring innovation, improve people's quality of life as well as encourage healthy living". The European Commission has created a policy on transformation of health care in the Digital Single Market where it is harnessing the potential of data to empower citizens and build a healthier society. With digital health we can integrate healthcare systems across EU, personalize health research, diagnose and treatments and have a citizen-centred health service instead of country centred health service and increase prevention of diseases and bad health.

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.

Together with the opportunity to use digital health to improve overall health outcomes of EU citizens there are several challenges linked to maintain control of own health data, privacy issues, ethical concerns, etc.

Objectives

ECPC will look for innovative ways to raise awareness on the opportunities associated with the implementation of digital health without ignoring the challenges that go with it for disadvantaged groups, for instance (people living in rural areas or the elderly) or due to privacy and ethical issues. We will empower our members disseminating information and good practices across Europe.

Actions

ECPC will develop a survey to best understand the gaps in information and awareness of cancer patients about the opportunities and challenges of digital health in order to increase efficiency, bring innovation, improve people's quality of life during treatment and survivorship and encourage healthy living. The European survey will identify national gaps, barriers, good practices and lessons learnt from relevant stakeholders and organizations around Europe. The results of the survey will be submitted for publication in a peer reviewed and indexed scientific journal.

Deliverables

- Survey among cancer patients to identify national gaps, barriers and good practices
- Publications on gaps and opportunities
- EU parliament event

Timeframe

- Month 2-6: Survey design and implementation
- Month 8-10: Evaluation of the survey results
- Month 10-12: Presentation of the survey results in an EU Parliament event
- Month 10-12: Publication of the survey results

2.11 Cancer and Inequalities

Duration: January 2021 – December 2021

Context

With a growing burden of cancer diagnoses increasing, the access to appropriate, affordable, and fair treatments is crucial in order to avoid inequalities between different countries, different social and ethnic groups. A

combination of information, awareness raising, lower exposure to risk factors, better access to screening programs, better access to health services and better capacity to absorb the social and financial consequences of cancer, favours certain privileged groups to have better outcomes than other groups of society. In Europe alone, we have significant social inequalities between and within European countries, social and ethnic groups. This affects the incidence of cancer, the survival and mortality rates. For example survival is often much lower in Southern and Eastern European countries than the European average which indicates that access to quality cancer care is not uniform across all European regions. Very little is known about inequalities among social and ethnic groups.

The large disparities in European cancer care both among and within countries remains a long-term priority for ECPC. For every Elsa in Sweden who has an 86% chance of survival following treatment for breast cancer, there is an Ilsa and Elze just across the Baltic Sea in Latvia and Lithuania whose survival chances drop to 69% and 66% respectively. National cancer plans lack coordination among Member States, are often based on inadequate information and, due to a lack of patient-centricity, fail to take account of the multitudes of ways that cancer affects individuals. Inequalities can be addressed by increasing patients' access to up-to-date information, decreasing the variability in cancer screening rates, providing equal access to cancer treatments and rehabilitation services, addressing the fiscal and governance deficits in health planning and implementing patient-centred cancer survivorship plans.

Efficient and affordable cancer care should not be depending on your social status or on what country you live in. There should be the same access to treatments and care for all patients being given a cancer diagnose. Societies need to be informed and educated about risk factors, lifestyle choices and available treatment options equally within all of Europe and within all national communities and regions. This will enable equal treatment for all patients in Europe equally and give everyone a fair chance of survival.

Objectives

After our members raised the alarm in 2014 over increasing health inequalities across Europe, ECPC acted decisively as part of the European Cancer Concord (ECC). We launched the Cancer Patients' Bill of Rights in collaboration with Members of the European Parliament and engaged academics and our members in drafting the White Paper 'Challenging the Europe of Disparities.' Launched at the 2015 European Cancer Congress in Vienna, the White Paper details the reality of disparities across Europe and our view on addressing them.

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 is 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' also remains a powerful resource for shedding light

on inequalities faced by cancer patients in Member States.

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

Actions

ECPC is the voice of patients, making sure that all patients are taken into equal consideration. ECPC will develop a literature review and possibly a survey to understand social and ethnic inequalities in terms of access to information, diagnosis and treatment for cancer patients in several EU countries. We will then advocate for policy changes enabling lower income countries to take advantage of the same information and health care updates that higher income countries have easy access to. ECPC will continue to advocate for treatment options to be readily available throughout and within each European Member State in order to prevent social and health inequalities and decrease the gap that exists today based on the degree of privilege of patient's community and country.

ECPC will run a raising awareness social media campaign and will organise an online webinar for patient organisations and other relevant stakeholders and a broader workshop at the ECPC Annual Congress 2021. ECPC will also organize national trainings or workshops to raise awareness at country level and among specific disadvantaged groups. We will also provide more detailed guidance on cancer inequalities in their countries and seek input from members in countries where more effective plans are implemented, as good practices can be shared.

Deliverables

- Literature review on existing inequalities
- Social media campaign
- Online webinar for patient organisations and other relevant stakeholders
- Workshop at the ECPC Annual Congress 2021
- National trainings to activate member patient organisations

Timeframe

Month 3-9: Literature review implementation

Month 9-10 Social media campaign

Month 9-10: Online webinar for patient organisations and other relevant stakeholders

Month 6: Workshop at the ECPC Annual Congress 2021

Month 7-12 National trainings to activate member patient organisations

2.12 Palliative and complementary care

Duration: January 2021 – December 2021

Context

Palliative and complementary care is a fundamental component of the cancer patient's journey, but it is often neglected. 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. In order 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 its turn can also improve treatments adherence and outcomes. Treating patients should not only be based on dosage of medicines but should also consider the patients with multi-disciplinary teams that look at all the aspects the patient needs to be treated in order to feel better and even increase adherence and outcomes of medical treatments.

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 a 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 1-6 Establishment of a working group

Month 3-5 Preparation of the campaign and the factsheets

Month 6-9 EU Parliament event

2.13 Cancer Mission

Background

At the European Research & Innovation days in September 2020, the EU Mission board handed over a final recommendation on proposed missions for Horizon Europe. The current five missions are a commitment to solve major societal challenges. One of the missions is dedicated to cancer, namely the “Conquering Cancer: Mission possible”.

The Cancer Mission is based on three pillars: to have more prevention, better treatments, more lives saved, and a better quality of life for patients and their families living with, and after, cancer. The mission has a timeframe of 10 years and will start by the end of 2020 and proceed until 2030. The goal is to save more than three million lives and resulting in more people living longer and better.

Importance to Cancer patients

This specific mission is addressing all types of cancer in all phases. That means from prevention of risk factors, to survivorship support and end-of-life care. It is a European Union project meaning it is spreading across all member states of the EU. This affects and includes patients with rare cancers, patients who are children, adolescence, adults, and old people. Socially and economically vulnerable families and people living in remote areas are also considered. When understanding the processes and factors that are leading up to cancer a bit better, actions on prevention, treatment and quality of life can be improved.

ECPC Actions

ECPC will be the voice of patients and help shed light on the different problems in each of the different cancer types in order for all and everyone to be included. We will disseminate information and gather relevant data in order to enable the EU Commission to have a full picture and be able to proceed accordingly.

2.14 Europe's Beating Cancer Plan

Background

Every year, in an annual program, the European Commission plan, prepare and propose new European legislations in an action called "Right of initiative". They make their political commitment to deliver on a certain number of priorities during a given calendar year and before finalising it, citizens, businesses, civil societies, public authorities or any other stakeholder who may be affected can have their say in the process. The way this is done is through the roadmaps which the Commission uses in order to define their scope, whatever it may be. The roadmaps describe the problem to be tackled and what objectives the Commission wishes to meet. They explain why an EU action is needed, outline policy options and describe the main features of the consultation strategy. Once the roadmap is drafted, the people mentioned above can have "have their say" on it in a consultation process which is announced with a clear deadline. Post deadline, the Commission will consider the feedback given to the roadmap when further developing the scope or when evaluating several related laws and policies.

In March 2020 the European Commission presented its Roadmap on the Europe's beating cancer plan. In its roadmap the Commission described the overall objective and aim of the EU Beating cancer plan and how they intend to reach their objectives. The plan is to improve the prevention, detection, treatment and management of cancer in the EU while reducing health inequalities between and within Member States.

Importance to Cancer Patients

The cancer plan has five important topics which it will focus on, each very important for cancer patients. The different topics are Prevention, Early detection and diagnosis, Treatments and care, Quality of Life for cancer patients, survivors and carers, and lastly Knowledge, data and scientific evidence. This is part of the Commissioner's initiative to by 2030 reduce premature mortality from chronic diseases, including cancer, by one third. If objectives are met, it means better outcomes for everyone currently living with cancer and anyone who in the future might be diagnosed with cancer when better diagnostic tools and treatments are available.

Patients currently living with Cancer and their carers have a great opportunity to give their feedback and opinions on what issues that are important and how them dealing with cancer on a day to day basis affects them.

ECPC Actions

ECPC will drive the patient voices in all the five topics of the EU Beating cancer plan roadmap. ECPC will help gather the patients voices as well as stand up for those who cannot speak themselves. We will make sure that the patient perspective is always included into developing new strategies in all topics and that any improvement of quality of life for survivors, carers and patients are being developed with the consideration of what is important for the people they are developing it for. ECPC will help disseminate, communicate and educate within their patient organization networks and other stakeholders.

3. Health and Research

3.1 Big Data and Personalised Medicine

3.1.1 QUALITOP

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

The logo for QUALITOP, featuring the word "QUALITOP" in blue capital letters. The letter 'Q' is stylized with a small circular icon containing a DNA helix and a flower-like shape.

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.

Lead Coordinator: HOSPICES CIVILS DE LYON FRANCE

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

Integrated and standardized NGS workflows for Personalised Therapy

Type: IMI project co-funded by Horizon2020

Duration:2020-2024

The logo for Instand NGS4P, featuring the word "Instand" in blue, "NGS" in large green letters with a blue DNA helix passing through them, and "for Personalized Therapy" in blue below.

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.

Lead Coordinator: MEDIZINISCHE UNIVERSITÄT GRAZ, AUSTRIA

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).

3.1.3 LEGACy

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

Type: Horizon 2020

Duration: 2019-2022

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.



Lead Coordinator: INCLIVA Health Research Institute

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

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



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.

Lead Coordinator: University of Aberdeen

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.

3.1.5 Lifechamps

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 to improve 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 to stratify 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

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

Description:

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).



Tasks:

WP5 AI solutions in clinical setting (4 PM):

- Task 5.2: To evaluate the clinical and economic impact of using polygenic risk information for decision support and primary prevention of breast cancer. (FIMM, UNITO, HUS, UNISI, ECPC) (M1-M60).
- Task 5.2.4 Counselling first-degree relatives of breast cancer patients (FIMM, UNITO, HUS, UNISI, ECPC) (M36-M60)
- WP6: Ethical and legal framework for AI and genetics (10 PM)
- Task 6.2: Qualitative assessment of perception of genetic scores and genetic reporting tool (TUM, BBMRI, VUMC, UTARTU, ECPC) (M12-M48)
- Task 6.3: Framework for trustworthy AI and Ethical guidance principles for genetic score-based risk prediction and personalised medicine (TUM, BBMRI, ECPC) (M48-M60)
- WP 7: Project Coordination and Management (10 PM)
- Task 7.1: Internal project management and coordination (FIMM, ECPC, TTOP) (M1-M60).

- Task 7.2: Coordination of the periodic technical and financial reporting (FIMM, ECPC, TTOP) (M1-M60).
- Task 7.5: Planning and hosting of project meetings (FIMM, ECPC, TTOP) (M1-M60)
- WP8: Dissemination, exploitation, and sustainability of the project outcomes (30 PM)
- Task 8.1 Co-creation of a communication and dissemination plan (FIMM, ECPC) (M1-M6)
- Task 8.2: Communication and dissemination activities (FIMM, ECPC) (M1-M60)
- Task 8.6: Plan for exploitation of project results (FIMM, ECPC, TTOP) (M1-M60).

3.2 Knowledge Sharing Networks

3.2.1 iPAAC

Innovative Partnership for Action Against Cancer

Type: Joint Action (JA) – Cancer Control

Duration: 2018 – 2021

Aim: Cancer continues to present one of the key public health challenges in the European Union. Targeting both EU-level policy-makers and decision-makers at national, regional and local level, iPAAC focuses on implementation of the outcomes of the European Partnership for Action Against Cancer (EPAAC) and Cancer Control (CanCon), and constantly expands its activities to new cancer control issues such as genomics, innovative therapies and the use of registries.



This Joint Action also hopes to provide better efficacy for dealing with neglected cancers, through the development of new key indicators to assess clinical patient pathways and healthcare-related costs of cancer and its intervention, particularly in the case of pancreatic cancer. At the European Union level, iPAAC adds value by enhancing collaboration in the field of cancer with extensive exchange of good practices, successful implementation of different programmes and gradual reduction of the cancer burden. At Member State level, iPAAC employs its Roadmap on Implementation and Sustainability of Cancer Control Actions to support national, regional and local decision-makers in implementing innovation.

Lead coordinator: Tit Albreht, National Institute of Public Health Slovenia (NIJZ)

What ECPC does:

ECPC integrates the patient's voice within iPAAC by contributing to guidelines for cancer information and registries, advising on the selection of epidemiological indicators on cancer prevalence and survivorship, participating in a consensus

meeting to define neglected cancers using the case of pancreatic cancer, and supporting a paradigm shift on the use of genomics. ECPC also contributes to the successful dissemination of the project's deliverables and is collaborating to organise an expert workshop and 2 conference meetings actively supporting networking and mapping of contacts.

3.3 Patients and Caregivers

3.3.1 PREFER

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

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

Duration: 2016-2021



Aim: PREFER is working to provide a set of systemic methodologies and recommendations to assess, engage and include patient perspectives during the development, approval and post-approval of new therapies, providing a better understanding of recommended best-practice approaches. The project gives an indication of how patient preference studies can provide valuable information to support decision-making and establishing recommendations to support the development of guidelines for industry, regulatory authorities and HTA bodies on how and when to include patient perspectives on the benefits and risks of medicinal products.

Lead Coordinator: Uppsala University

What ECPC does: ECPC leads three other patient organisations in the Patient Advisory Group (PAG) to ensure that the methodologies identified are consistent with the specific views, experiences and preferences of patients, from contributing to the overall project design, setting up patient focus groups, and reviewing surveys, study protocols and guidelines, to the successful communication and dissemination of the project's deliverables. ECPC sits on the project Steering Committee and Advisory Board as the Lead Patient Representative influencing research priorities to match patients' needs and the inclusion of quality of life indicators.

3.3.2 DIAdIC

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

Type: Horizon 2020 Project

Duration: 2019-2023



Aim: DIAdIC will develop and evaluate two different methods of administering psychosocial and educational interventions: a face-to-face method provided in the patient and caregiver 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.

Lead Coordinator: Vrije Universiteit Brussel

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.

3.4 Palliative Care

3.4.1 Palliative Sedation

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

Type: Horizon 2020 Project

Duration: 2019-2023



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.

Lead Coordinator: Radboud University Medical Centre

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 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 adopted for PS.

3.5 Treatments

3.5.1 Immune-Image

Specific Imaging of Immune Cell Dynamics using novel tracer strategies

Type: Funding from the Innovative Medicines Initiative 2 Joint

Duration: 2019-2024



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.

Lead Coordinator: Amsterdam UMC

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. This involves conveying information about the trials to confirm safety and to evaluate the clinical potential of novel immunotracers to ECPC cancer patient community and other relevant European patient organisations. ECPC involves multiple patient organisations who would benefit from the project outcomes.

3.5.2 ImmunoSABR

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

Type: Horizon 2020 Project

Duration: 2017-2023



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.

3.6 Scientific Committee and Advisory Role

3.6.1 EUCANCan

European-Canadian Cancer Network

Type: Horizon 2020

Duration: 2019-2022

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.

Lead Coordinator: Barcelona Supercomputing Center

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.



3.6.2 PREDICT

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

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.

Lead Coordinator: Maastricht University

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.

3.6.3 HTx

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

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.

Lead Coordinator: Utrecht University

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.

ECPC Director Antonella Cardone sits on the project's Stakeholder Advisory Board, the HTx Forum. She 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.

3.6.4 ELBA

European Liquid Biopsies Academy – Towards widespread clinical application of blood-based diagnostic tools

Type: funded by the Marie Skłodowska-Curie Actions, part of the EU's Horizon 2020 Programme. Duration: 2018-2021.



Aim: ELBA will educate 15 Early Stage Researchers with the skills to face these obstacles in key disciplines of molecular biology and medicine, bioinformatics, biostatistics, mathematics, computer science, social sciences, health economics and technology assessment. ELBA will make scientific advances towards widespread implementation of blood-based diagnostics tests, create a sustainable network to foster long-term multidisciplinary relationships to accelerate clinical translation of blood-based diagnostics tests and publish a roadmap towards liquid biopsy test development.

Lead Coordinator: VU University Medical Center

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 also represented on the Project Advisory Board to monitor project progress and provide input on the design and direction.

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 data base is not sufficient anymore to manage ECPC contacts in an efficient and effective manner.

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 will be 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

Timeframe and milestones

Month 1 Start of the project

Month 1-3 Hiring or identifying and briefing a person to contact each member (2 months)

Month 1-3 Quality check

Month 4-10 Developing the database (6 months)

Month 9 Delivering the database populated with updated information

Month 10 Testing the database and trouble shooting

Month 12 Launch of the new data base

Deliverables

- Updated database in an Excel table
- Professional Member database delivered

4.1.2 Survey on Members' needs

Duration: 12 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.

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 strengthening ECPC membership identifying members' strengths, challenges and needs.

Actions

- Disseminating the questionnaire to members that have not answered yet
- Collecting the answers
- Reviewing and analysing the answers
- Reporting and addressing the findings

Timeframe and milestones

Month 1 – 8 Dissemination of the questionnaire to members

Month 9 Analysis of the answers

Month 10 – 12 Drafting the report and recommendations

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

4.2 Bonding with our Members

4.2.1 Annual Congress

Duration: 8 months

Context

The Annual Congress is the fundamental event where ECPC meets all its members and partners. It is a unique opportunity for engagement, capacity

building and networking. Some uncertainties are linked to it as the COVID pandemic has set some restrictions, but our main goals remain, and we will make our best efforts to consolidate our Annual Congress.

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 Annual Congress 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: 6 months before

Month 2 Starting accommodation booking: 4 months before

Month 4 Draft programme and promotion of the event: 2 months before

Month 5 Press relations: 1 month before

Deliverables

Congress agenda

Congress report

4.2.2 General Assembly

Duration: 6 months

Context

The General Assembly usually takes place right after the Annual Congress 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

In 2020, the General Assembly was held virtually on the 21st of November. Thus, for 2021 edition, it remains to be seen if COVID19 restrictions are still in place. We will act in accordance with the measures to preserve everyone's security.

Objectives

- To increase the sense of ownership of members
- 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

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 session with Board Members to answer questions and prepare for the AGM

Timeframe / milestones

Month 4 Sending a mailing of information: two months prior to the event

Month 4-6 Collecting questions through mailings, social media and on the website and promoting the Live Q&A video: two months prior to the event + reminders every two weeks and then every week

Month 6 Live Q&A video: 2 weeks before the event

Deliverables

5. Communications and Awareness Campaigns

5.1 Make Sense of head and neck cancer campaign

Head and neck cancers are the 6th most common types of cancer in Europe with more than 150,000 new patients diagnosed every year. There is little awareness among the public with many cases diagnosed at a late stage. Despite major advance 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 and 10% of patients show metastases at distant sites from the first presentation.

In recent developments, the release of RARECARE data sheds a new light on head and neck cancers which involve several anatomically diverse sites (e.g. 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. Most head and neck cancer patients are still diagnosed at advanced stage, experienced delay in starting the treatment and are not treated with multi therapy.

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 the 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 2021. 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 2021 project are the following:

- To **raise awareness**, through a social media campaign and a webinar, of head and neck cancer across Europe among the general public and healthcare professionals in order to improve outcomes through earlier diagnosis and treatment
- To highlight the link between the **HPV and head and neck cancer** and communicate the need for action to slow the growing numbers of HPV-related head and neck cancers
- To emphasize the fact that **smoking and drinking** can greatly increase the risk of developing head and neck cancer.
- To communicate the **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 2021) and ESMO multidisciplinary care Head and Neck guidelines
- To explore among relevant stakeholders 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 refine the fact sheets 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 2021) 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 affecting outcomes of cancer patients' treatments and diagnosis, it is vital 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

Together with the HNC Society, ECPC will adapt the existing head and neck cancer survivorship guidelines for a European audience. ECPC will ensure that head and neck cancer patients' voice is represented in the guidelines development and we will include our member and HNC survivor Roberto Persio to oversee this process.

Deliverables

- Updated fact sheets and translation of the fact sheets on selected EU languages
- Webinar/event (agenda, invitation of speakers, invitation of participants, management of registrations, technical organization, moderation, report and follow up) in September during the Head and Neck Awareness Week
- Awareness campaign to promote the event and HNC awareness week on social media, including video messages or quotes of HNC patients
- Campaign toolkit to maximize the interest of our members and stakeholders (social media calendar, toolkit, mailing)
- Press relations to maximize media interest and coverage (press kit, press release, direct contacts with journalists and follow up, press cutting)
- Updated educational [webpage](#) on head and neck cancer on ECPC website

- Call to policy makers action and its translation in selected EU languages
- Guidelines for HNC patients co-developed with patients to secure the patient perspective

Timeline

January - March: identify patients and stakeholders to involve directly in the project, identify the content for updating the fact sheets

April: organise focus group to update the fact sheets

April – August: finalisation of materials, translations and graphic layout of any relevant materials for the campaign

June - September: Preparation and implementation of the awareness campaign

5.2 Fundraising – communications (toolkit)

Duration 2 years

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. Fundraising is one of the main challenges ECPC members face.

Objectives

- To support ECPC members to keep their independence from public and private funds diversifying the source of financing
- To sustain and to develop their activities.

Actions

- Elaboration of fact sheets and webinars or face to face trainings following the basic steps of a fundraising policy, strategy and project:
 - o Crowd funding
 - o Fundraising event: conference, sport event, charity sale, exhibition...
 - o Donations and legacy
 - o Legal obligations related to fundraising
 - o Partnering with a private company
- Write case studies on the most successful practices of our Members

Timeframe / milestones

Month 6-7 Writing and laying out fact sheets

Month 9-12 Organising webinars: June 2021, September 2021, June 2022, September 2022

Month 1-12 Articles on best practices all year long

Deliverables

- Fact sheets
- Webinar report/s

5.3 Nutrition

Duration: January 2021 – December 2021

Context

Nutrition is a crucial component of cancer treatment and rehabilitation as it helps patients better cope 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 developed a pilot survey on nutrition and its importance on the treatment and life of cancer patients. As preliminary data suggested that discrepancies existed between patients' expectations and the answers they receive from physicians, a second survey was developed in 2016. A total of 907 patients and survivors were surveyed in 10 European countries including: Finland, Italy, Spain, Czech Republic, Greece, Denmark, Slovenia, Romania, Poland, and Bulgaria. The results were presented at the 2017 Annual Congress and at ESMO and a booklet was launched in November.

In March 2018, ECPC launched the Nutrition awareness campaign with materials made available in ten languages. The Living Well During Cancer Treatment was also presented at the ONCA Congress in 2018 and was featured in the EONS Satellite meeting during the ESMO 2018 Congress.

In 2019 ECPC translated the "Living Well During Cancer Treatment" booklet into Italian, Greek, Spanish, Polish, Finnish, Danish, Slovak and Bulgarian. The results of the survey were also published in two editions of the Journal of Cachexia, Sarcopenia and Muscle.

In 2020, ECPC continued the Cancer and Physical Activity Awareness Month in March, organised a webinar in Romania and Czech Republic and incremented the booklet with patient stories.

Objectives

- To inform and empower patients on the importance of nutrition during their cancer treatment and after cancer

- To raise awareness of the importance of Nutrition among policy makers at national and EU level

Actions

Nutrition and Physical Activity Awareness Month is celebrated every year in March. It is dedicated to increasing awareness on the importance of nutrition and physical activity for people with cancer and it is aligned with the American National Nutrition Month, a campaign created annually in March by the American Academy of Nutrition and Dietetics.

The evidence-based Patient Guidelines summarised into fact sheets and messages will be updated and disseminated using social media, ECPC website and newsletter. The material will be also disseminated at any other relevant online or face to face event ECPC is participating, such as ISPOR, ONCA, EONS, ESMO and any other relevant conference.

ECPC will further build on previous work done by promoting the Charter of Rights at National level supporting the organisation of national events. ECPC will also plan an update of Series II of the “Living Well during Cancer Treatment Nutrition Patient Booklet” addressing more specific cancer patient concerns.

Deliverables

- “Living Well During Cancer Treatment” booklet printed into different languages
- National events
- Updated version of Series II of the “Living well During Cancer Treatment Nutrition Patient Booklet”

Timeframe

Month 1-3: Update Nutrition and Physical Activity Awareness Month materials and organisation of the social media campaign

Month 1-6: Updated version of Series II of the Living well During Cancer Treatment Nutrition Patient Booklet

Month 3-12: National Events

5.4 Sport and Physical Activity for Cancer patients during and after treatment

Duration: January 2021 – December 2021

Context

Twenty years ago, when cancer treatments were very toxic and mortality was higher, if a patient had asked the oncologist if physical activity was good during

treatment, the advice would have been to avoid physical exertion and to preserve the strength to deal with treatments.

Already in 2012, several studies showed the following:

- Walking is a workout that can be practiced without difficulty by most cancer patients.
- Even home walking exercises are an effective intervention for patients suffering from various types of carcinoma (including breast, pancreas and lung cancer).
- Cancer patients who continue to train even after diagnosis have a lower risk of mortality and recurrence and that exercise reduces the number and intensity of side effects (peripheral neuropathy, fatigue, depression, sleep disorders, cardiovascular toxicity, existential and psychological distress).

However, over the past two decades, considerable progress has been made and numerous studies have highlighted the efficacy of physical exercise in the therapeutic pathway of the cancer patient. Today numerous studies have highlighted the effectiveness of physical exercise in the cancer patient's therapeutic pathway, also to reduce the number and intensity of side effects.

Two very recent French studies presented at the ESMO 2018 Congress highlight how sport should rightfully become part of treatments for cancer patients, both during chemotherapy and radiotherapy, and subsequently, because it significantly improves quality of life and general well-being.

A retrospective analysis of 100 studies conducted on thousands of patients whose behavior was assessed with respect to physical activity after the diagnosis of cancer was recently published. Compared to patients who have not carried out physical activity or performed it to a limited extent, patients who have continued training after diagnosis have had a lower risk of mortality and relapse, as well as having fewer side effects and less intensity.

Despite all this evidence, training is not yet considered an indication for cancer patients, while physical activity levels tend to decrease significantly during treatment and remain low even after treatment.

Objectives

The existence of a relationship between physical activity and survival to neoplasms is therefore confirmed by an ever more consistent body of experimental clinical evidence. Physical exercise and sport must therefore become part of the treatments intended for cancer patients both during chemotherapy/radiotherapy and subsequently, because it significantly improves symptoms, quality of life and general well-being. So ECPC aims at:

- Breaking down the cultural and organizational barriers that prevent the treatment team from recommending physical activity to patients and patients to consider exercise as an ally during and after cancer
- Including physical exercise in clinical practice as a therapy

- Including sport among the useful recommendations for a return to a normal, active and productive life after cancer

Actions

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

- A literature review on the latest scientific evidence to support the relationship of physical activity and cancer treatment and survival
- Creation of an updated informative brochure on physical exercise and sport as a therapy for all purposes in cancer treatments and as an ally for the return to life after cancer.
- Wide dissemination of the brochure, created with the collaboration of leading oncologists, surgeons, radiotherapists and psycho-oncologists through ECPC website, social media, press release and press conference and any other possible communication channel
- Implementation of an awareness campaign aimed at the general public and patients
- Implementation of an awareness campaign aimed at general practitioners and oncologists

Deliverables

- Literature review findings
- Revised brochure to inform cancer patients, policy makers and health care professionals
- Communication plan
- Awareness campaigns reports

Timeframe

Month 1-3: Conduction of the literature review

Month 3-4 Update of the informative brochure on physical exercise and sport

Month 5-10: Preparation of the awareness campaigns

Month 11-12: Awareness campaign

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 2021 ECPC aims at strengthening even more those strategic alliances.





European Cancer Patient Coalition

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