



European Cancer
Patient Coalition



Action Plan 2020



**European Cancer
Patient Coalition**

Publisher

Published by the 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 2019 achievements

2019 was a year of more than one change in ECPC, starting with a new board, a new Director, new staff members, new branding. 2019 was also a year of changes on the political level with European elections and national elections in more than one Member State (MS), that led to a new European Parliament and a new Commission. Challenges with which ECPC will have to prove its resilience, adaptability and commitment to its mission.

In 2019, ECPC elected a new Board with Kathi Apostolidis stepping up to the role of President after two terms as Vice President, and renewal of the board with six new members, representing ECPC member organisations from Poland, Italy, Ireland, Romania, Sweden, The Netherlands. ECPC's Past President, Francesco de Lorenzo, now serves as the Coalition's Chair of the Scientific Committee to support and advise the work of the Board on cancer policy, research projects, strategic partnerships and any other activity implying the creation and divulgation of scientific information. As Past President, he will continue attending Board Meetings with a consultative role.

ECPC, after 16 years, changed in 2019 its branding, first launched in June 2019 at the Annual General Meeting. The new branding adopts a new more modern and attractive logo, reminding the letter C, the first letter of the word cancer but also a waving cancer "ribbon", in a more welcoming colour palette of warm Green, Blue and Grey. The logo and new stationery are part of the image renovation of ECPC that will be completed with the launch of the new website later in 2019.

In order to inform the candidates for the EU elections about the key current issues in cancer policy, but also to be used as a quick cancer and health care policy reference for newly elected MEPs, ECPC published its Manifesto for the European Elections 2019 and will also publish in the 4th quarter 2019, a Handbook.

The Manifesto calls on Members of the European Parliament (MEPs) to support the ECPC mission to overcome inequalities in Europe by embracing innovation, enabling cross-border collaboration and promoting survivorship care and research programmes. The Handbook, with useful information for newly elected MEPs, will facilitate building new relationships and policy partnerships with new MEPs, as well as it will serve to consolidate and strengthen the partnership with re-elected MEPs.

ECPC completed its work on the Joint Action on Rare Cancers (JARC), continued its involvement in Working Parties and Committees of the European Medicines Agency (EMA), in TRANSCAN II, ECIBC-European Commission Initiative for Breast Cancer, iPAAC and on the Euracan-European Reference Networks (ERNs) and further established its role in the Innovative Partnership for Action Against Cancer (iPAAC).

In July 2019, the final event of the EU funded FP7 project eSMART, took place in Brussels, as ECPC deliverable. The event with presentations on the importance of digital technology in cancer supportive care, the impact that eSMART can have on cancer patients QoL and on freeing time of cancer specialist physicians, as well as the role of specialized cancer nursing on the outcomes of cancer patients, were highlighted and applauded by an audience of project partners, representatives of the European Commission, European cancer medical societies and other cancer care stakeholders.

Work on other European Union funded projects continued, including 8 Horizon 2020 projects (DIAdIC, EUCANCan, H2020MM04, HTx, ImmunoSABR, LEGACy, PalliativeSedation, TRANSCAN-2) 4 Innovative Medicine Initiative (IMI) projects (BD4BO DO-IT, BD4BO PIONEER, Immune-Image, PREFER), 2 Innovative Training Networks (ITN) (ELBA and PREDICT) and 1 Seventh Framework Programme (FP) project (eSMART). Over 20 new project proposals were submitted, and 4 new projects were approved by the European Commission with ECPC extensive role identified. A new project was funded by a private foundation on promoting the Right to be Forgotten policy and law, building on the success of the pertinent laws in France and Belgium.

New innovative approaches to cancer treatment, new diagnostic methods, introduction of big data and artificial intelligence to the diagnosis, treatment and prognosis of cancer, make the object of the majority of the new project proposals. ECPC follows closely the developments in these fields and raises awareness about them e.g. personalized medicine, immunotherapy, biologic and biosimilar medicines, as well as new cancer diagnostics, including new biomarker panels, NGS-New Generation Sequencing and WGS –Whole Genome Sequencing. ECPC follows with great interest the developments in the new treatment with Chimeric Antigen Receptor (CAR) T-cells for certain types of blood cancers. CAR T-Cell treatment is a therapy that involves genetic modification of patient's autologous T-cells to express a CAR specific for a tumor antigen. Large numbers of the CAR T-cells are grown in the laboratory and given to the patient by infusion. CAR T-cell therapy is being studied in the treatment of some types of blood cancer.

ECPC, as the voice of cancer patients in Europe, has taken a prominent role in the high-level discussions in the early mission-oriented approach to cancer public dialogue and will continue to engage with the oncology community in the Cancer Mission. ECPC with its then President, was an invited speaker, at the Vatican Meeting in November 2018 – organized by the European Academy of Cancer Sciences and the Pontifical Academy of Sciences - to discuss the mission-oriented approach to cancer for generating and contributing ideas to the framework and functioning on the Cancer Mission in Europe.

The European Academy of Cancer Sciences (EACS) is an independent advisory body of eminent oncologists and cancer researchers, placing science at the core of policies to sustainably reduce the death and suffering caused by cancer in Europe. EACS was initiated by Nobel laureates and aims to provide authoritative recommendations in the field of cancer research and care to EU and national institutions and policymakers. ECPC Past President will continue to represent the organization within the EACS Board of Directors and the Science Policy Committee and thus, the interests of European cancer patients.

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. Patient organizations can act as the missing link between all these stakeholders, always keeping in mind appropriateness and sustainability. ECPC, based on its unique expertise and perspectives, can be the bridge between research and healthcare and work efficiently with both. To this purpose, it will continue to engage with the oncology community and the European Commission in 2020, and beyond, on the principle of **"Science with and for Society"**.

A primary aim of the Cancer Mission should be to achieve the long-term survival of 75% of patients with cancer by 2030 by combining innovative prevention, treatment strategies, rehabilitation and multidisciplinary follow-up. The European Commission nominated in June the Chair of the Cancer Mission Board and published a call for the expression of interest from qualified candidates for participation in the Cancer Mission Board. The successful candidates were announced in August but no patient representative was among them. ECPC expressed its surprise for this omission in a press release attached at the end of the Action Plan.

ECPC collaborated closely with its Members across Europe on several awareness-raising campaigns, including bladder cancer, supportive care, cancer patient caregivers, cancer-associated thrombosis, head and neck cancer, pancreatic cancer, physical activity and nutrition, 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 its 447 Members is essential for the work of the organisation.

Several scientific papers, authored or co-authored by ECPC, were published in authoritative Journals including:

- ✓ “The European Cancer Patient Coalition and its central role in connecting stakeholders to advance patient-centric solutions in the mission on cancer”,
- ✓ “Cancer Core Europe: A translational research infrastructure for a European mission on cancer”,
- ✓ “Cancer survivorship: an integral part of Europe’s research agenda” all published in the Molecular Oncology Journal and
- ✓ Nutritional and metabolic derangements in Mediterranean cancer patients and survivors: the ECPC 2016 survey published in the Journal of Cachexia, Sarcopenia and Muscle

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.

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

1. The European Cancer Patient Coalition Objectives

The main objectives of the 2020 Action Plan are to support and advocate for cancer patient rights, to develop a strong engagement with the newly elected European Institutions members, to strengthen the connection with ECPC members and partners and to assure continuity during a period of many changes in both the internal and external environment. In order to uphold this commitment, the newly elected Board works in close collaboration with the Secretariat to develop ECPC strategy for 2019-2022.

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 the outcomes of the 2016-2019 Action Plan and Strategy and to follow and intervene in, where appropriate, the main EU health, research, and other relevant policy topics.

In 2020, the European Cancer Patient Coalition will focus on developing the following main policy themes:

- Health technology assessment
- Innovative Partnership for Action Against Cancer (iPAAC)
- Rare cancers
- Survivorship care
- Social disparities in Europe
- Supporting cancer carers in Europe
- Personalised medicine
- Right to be Forgotten
- Cancer Mission Europe

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 2020 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 2020, 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, 7 Horizon 2020 projects (DIAdIC, EUCANCan, HTx, ImmunoSABR, LEGACy, PalliativeSedation, TRANSCAN-2), 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 will begin work on its first project funded by the European Institute of Innovation and Technology (EIT) Health, “Empowering European Patients in Radiation Oncology” (E-PRO). ECPC will also be kicking off three additional Horizon 2020 projects (LifeChamps, QUALITOP, Instand-NGS4P).

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 six years ECPC has seen its membership almost double, renewed contact with old and new members, had the opportunity to meet many of them at the Annual Congress and AGMs. However, for ECPC to maintain such trust, it is necessary to keep providing Members with quality services and to increase such 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 2020 education and capacity building objective is 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 strategy to interact with Members, boost collaboration, and build a well organised “tening and responding system”. ECPC will encourage more and deeper involvement of Members in 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 2020, the main objective will be to implement a detailed communication strategy and an annual communications plan. This will address 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.

A major improvement in 2020 will be the new ECPC website also incorporating the new branding logo, colours and design. The work on the new website will be finalised by the end of 2019 and consolidated throughout 2020.

Awareness campaigns on HPV-human papillomavirus, head and neck cancer, prostate cancer, personalised medicine, pancreatic cancer, nutrition and physical activity, bladder cancer, non melanoma skin cancer will continue in 2020, while new ones will be added.

1.5 Strategic Alliances

Between 2013 and 2019, ECPC established and consolidated its relationship with several other non-governmental organisations and European Academic and Research Institutions. In 2019, a new Memorandum of Understanding was signed with the Toxic Neuropathy Consortium (TNC). Among others, the Memorandum of Understanding signed with the European Society for Medical Oncology (ESMO) and the Cancer Drug Development Forum (CDDF) will ripen in 2020, contributing to a compelling pack of joint initiatives.

In relation to strategic alliances, the objective for 2020 is to build upon the established partnerships in order to possibly expand them in new areas serving the needs of ECPC members and to, possibly, enhance new partnerships relevant to the implementation of the new Strategy 2019-2022.

1.6 How to read the Action Plan 2019

ECPC action plan outlines the main proposed activities for 2020. 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: Ongoing, January – December 2020

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 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”, where access to life-saving cancer medicines was delayed for years mainly due to difference in Pricing & Reimbursement methodologies and HTA evaluations. An 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 P&R at Member State level. The European Parliament has already unanimously approved its negotiation position in February 2019 for interinstitutional 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 e-module, country-based workshops will be organised in Poland and Greece.

The challenge 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 under the Croatian and German Presidency of the Council of the European Union in 2020.

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 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 these 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, 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 the medicine, thus allowing to inform the real value of medicine at national level.

ECPC aims at equipping its members by:

- Continuing to raise awareness among its members of the importance to be involved in the HTA process through the further dissemination of the HTA e-module, translation of it and the implementation of country-based 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 develop a booklet as a guide for patients and patient organisations at national level, explaining the patient involvement in Pricing & Reimbursement decision in their countries. It will primarily focus on the Member State domains of the HTA related to Quality of Life, patient and social aspects, as well as ethical analysis, legal aspects and value and economic evaluation.
- Building on the HTA workshops in Poland and Greece, ECPC will organise workshops for patient organisations at a national level and a broader workshop at the ECPC Annual Congress 2020. ECPC will activate member patient organisations, train and 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.

Timeframe and Milestones

Month 1-9 Organisation of National Workshops

Month 3-6 Organisation of the workshop at ECPC annual congress in June 2020

Month 2-6 Development of the content of the booklet/guide

Month 7-9 Translation of the booklet/guide

Month 10 Launch of the booklet

Deliverables

- Workshop at the ECPC Annual Congress 2020
- National workshops in partnership with ECPC Members
- Booklet/Guide for ECPC Members with detailed information on patient involvement in HTA bodies in the different Member States.

2.2 Innovative Partnership for Action Against Cancer (iPAAC)

iPAAC

Full name

Innovative Partnership for Action Against Cancer (iPAAC)



Type of Action

Joint Action (JA) – Cancer Control

Funding



iPAAC is funded by the EU's [3rd Health Programme](#) fostering health in Europe by **encouraging cooperation between Member States** to improve health policies that benefit their citizens. The programme aims to **support and complement** Member States health initiatives.

Project Duration

01/04/2018 – 31/03/2021 (3 years)

Lead Coordinator

National Institute of Public Health of the Republic of Slovenia

Member States involved are Belgium, Bulgaria, Croatia, Cyprus, Czech Rep., Finland, France, Germany, Greece, Hungary, Ireland, Italy, Lithuania, Malta, Moldova, Netherlands, Norway, Poland, Portugal, Romania, Serbia, Slovakia, Spain, Slovenia.

Website: <https://www.ipaac.eu/>

Context

Cancer continues to present one of the key public health challenges in the European Union. Targeting both EU-level policymakers 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 \(CANCON\)](#). It also expands its activities to cover new cancer control issues such as innovative therapies, neglected cancer and the use of registries and genomics. Molecular diagnostic, including genomic testing, is a prerequisite for personalised treatment and prevention which are becoming increasingly available to treat and manage a more extensive number of cancers. Patient access to genomic testing is still limited, and it is not available and

reimbursed in all EU Member States. There is a need for continuing education of healthcare professionals and suitable information for cancer patients and the general public.

Objectives

iPAAC will provide better efficacy for dealing with neglected cancers, through the development of new key indicators to assess clinical patient pathways and health care-related costs of cancer and its intervention, particularly in the case of pancreatic cancer.

By enhancing collaboration in the field of cancer with an extensive exchange of good practices, successful implementation of different programmes and gradual reduction of the cancer burden, iPAAC will add value to cancer control activities across the EU.

At Member State (MS) level, iPAAC will use its Roadmap on Implementation and Sustainability of Cancer Control Actions to support national, regional and local decision-makers in implementing innovative solutions on cancer control.

On Genomics in Cancer control and care, iPAAC will develop practical guidance for MSs on:

1. organizing the societal debate on ethical, legal and privacy issues on the use of genome information in healthcare
2. installing stratified screening by genetic testing of high-risk cancer patients
3. implementing precision genomics in medical care
4. how to deal with 'Direct to Consumer' testing
5. education and training on genomics of health professionals, policymakers and the citizens

ECPC will utilise the knowledge gained through participation in iPAAC and the outcomes of the joint action, to drive the effective implementation of national cancer plans and empower patients with knowledge about genomics in particular through active educational campaigns, such as ECPC Personalised Medicine Awareness Month.

ECPC Actions

ECPC integrates the patients' voice within the 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 for pancreatic cancer;

- supporting a paradigm shift in the use of genomics by driving patient and society understanding through active educational campaigns
- supporting the dissemination of the project's deliverables and results
- collaborating to the organisation of an expert workshop and two conference meetings
- Contributing to the guidelines for MSs on how to deal with 'Direct to Consumer' testing. These guidelines will include a statement document on cancer risk prediction and impact on the health of citizens to raise awareness of citizens and health care professionals awareness on 'Direct to Consumer' testing. The guidelines will also elaborate on the premise that each citizen should have access to organized certified genetic counseling in their country provided by a national health care system taking into account the local context
- Contributing to the guidelines for MSs on education and training on genomics of health professionals, policymakers and the citizens. This is an issue that must be approached with care, given the potential for misleading claims, but it does suggest that the public may be relatively uninformed about the scope for genetic screening services. It also introduces the problem of a possible democratic deficit, which arises when the general population is uninformed about a topic on which legislation is made. By focusing on cancer genomics, iPAAC can define actions for correct and complete information and education of citizens.

2.3 Rare Cancers

Duration: January – December 2020

Context

The public health challenge posed by rare cancers combines both the typical problems of rare diseases and cancers where the need for timely diagnosis and access to quality treatment is vital. The Joint Action on Rare Cancers (JARC) concluded with an event in the European Parliament in September 2019, which was organised thanks to ECPC and ESMO contacts. It aimed to integrate and maximize efforts of the European Commission and EU Member States to advance quality of care and research on rare cancers. The JARC recommendations, published in a book at the final conference, offer guidance for optimising the developments of the European Reference Networks (ERNs) in the area of rare cancer through synergies with Member State policies on rare cancers. The book includes a chapter written by ECPC in partnership with two other patient organisations reflecting the views of the rare cancer patient community and sets the basis for the next steps ECPC will put in place to ensure their implementation.

The European Parliament report, [adopted in February 2019](#), on Implementation of the Cross-Border Healthcare Directive highlighted shortcomings of the implementation of the Directive, providing a range of recommendations for the European Commission and the Member States relevant for ERNs. In 2016 ECPC established a Working Group on Rare Cancers (WGRC), which today counts on over 60 member cancer patient organisations across Europe, to guarantee that a large number of rare cancer patient organisations, representing different European countries and rare cancer types, would be able to contribute to the JARC implementation. In 2020 the WGRC will continue its work to implement the recommendations launched by the JARC at the EU Parliament in 2019 event and part of the book published on the JARC, as well as the European Parliament report.

Objectives

The formal activation of ERNs is a cornerstone in the EU cooperation on rare cancers, and the JARC is instrumental in helping them evolve optimising the creation of ERNs through the provision of operational support and professional guidance in relevant areas. [The ERNs is the only working structure of EU health cooperation involving more than 900 highly-specialised healthcare units from over 300 hospitals in 26 EU countries.](#) To drive change of care delivery for rare cancer patients in the EU, ECPC will use the chapter on patient engagement to inform our member patient organisations on the implementation of ERNs and support them in monitoring the implementation and sharing learnings with patient organisations in other Member States. WGRC has a role in disseminating information to patients on the existence of ERNs, and how to access them and to support the Member States nationally on selection of patients within national networks for referral to ERNs. ECPC will continue to provide information on the ERNs and their implementation on the ECPC website.

Actions

ECPC will build on the JARC recommendations and the European Parliament report on the implementation of the Cross-Border Healthcare Directive (2018/2108(INI)) adopted in 2019, which also highlighted shortcomings in its implementation to date and opportunities for improvement, such as:

a) Member States should work together to support the uptake of the reimbursement rules and their application to telemedicine and harmonise their reimbursement policies.

b) Member States and their health authorities should also address the legal and practical issues that are hindering the mutual recognition of medical prescriptions across the EU, and the EC should provide further support to facilitate this.

c) Member States should also support healthcare providers within the ERNs and integrate ERNs into their healthcare systems, adapting their legal and regulatory frameworks and referring to ERNs in their national plans on rare diseases and cancer.

The report also provides a range of recommendations for the European Commission and the Member States. Alongside the expert and patient recommendations, ECPC's Working Group on Rare Cancer (WGRC) will use these recommendations to work with patient organisations representing rare cancer patients at a national level to ensure their timely and appropriate implementation, that Cross-Border Healthcare Directive is functional and its provisions accessible in the interest of rare cancer patients. In addition, ECPC will endorse the ERN Board of Member States' recommendations to Member States to further enhance the integration process of ERNs into national healthcare systems.

Timeframe and Milestones

Month 1-9 Organisation of the WGRC

Month 4 and Month 9 Remote meetings (webinar) of the WGRC

Month 6 In-person meeting of the WGRC

Month 1-6 Development of the guidance document

Month 6 Launch of the guidance document at the ECPC Annual Congress

Month 1-12 Meetings with relevant stakeholders

Month 1-12 Dissemination activities

Deliverables

- WGRC Meeting at the Annual Congress 2020 and two webinars
- A guidance document for ECPC member on how to best use the JARC Recommendations included in the Patient Chapter
- Reports of meetings with Members of the European Parliament, to ensure sustained drive for European Commission to follow-up on the report on Cross-Border Healthcare Directive Implementation.
- Reports on Awareness and Dissemination of information on rare cancers, cross-border healthcare and ERNs.

2.4 Survivorship care

Duration: January – December 2020

Context

As many as 13 million patients will be considered long-term survivors in 2035, in need of professional and social support and demanding continuous research efforts into prevention of late effects and especially in order to facilitate full reintegration into society in all aspects.¹ Cancer survivorship has traditionally received little prioritisation and attention, and for a long time, the treatment of cancer has been the main focus of healthcare providers' efforts. There is an urgent need to look into the research on cancer survivors in Europe to inform the decision-making on survivorship care, rehabilitation and reintegration of cancer survivors. Patients living after a cancer diagnosis (i.e., prevalent cases) include those currently in treatment; those who have become cancer-free but still have a measurable excess risk of recurrence or death; and patients who can be considered "cured", as they have reached the same death rates of the general population². In 2017 ECPC, with the European Society for Medical Oncology (ESMO) and in collaboration with the International Psycho-Oncology Society (IPOS) created a Patient Guide on Survivorship available today in English, German, Greek, Spanish, French, Croatian and Italian. In 2019 ECPC also organised 2 workshops to disseminate it in Germany and France, and published an article in the [Journal of Molecular Oncology Cancer survivorship: an integral part of Europe's research agenda](#) written together with leading experts in the field. It is important to emphasise that most oncological treatments are multimodal, resulting in complex and sometimes unanticipated long-term effects that need to be monitored and, where possible, treated in a multidisciplinary manner following the recommendations of the Joint Action on Cancer Control (CanCon).

Objectives

Based on the CanCon recommendations and the ESMO-ECPC Survivorship Guide, ECPC will build the capacity building of member patient organisations to collaborate with medical oncologists' societies in their countries to drive the implementation of the Survivorship Guide recommendations in real life practice, starting from the recognition of the survivorship care plan as one of the cancer priorities. The survivorship care plan enhance the link between hospitals, oncologists and general practitioners, and ECPC will develop a guide on how to build a culture of survivorship care in every Member State, following the examples from Italy and Greece.

¹ Eggermont AMM, Apolone G, Baumann M, Caldas C, Celis JE, de Lorenzo F, Ernberg I, Ringborg U, Rowell J, Tabernero J, Voest E, Calvo F. Cancer Core Europe: A translational research infrastructure for a European mission on cancer. *Mol Oncol*. 2019 Mar;13(3):521-527. doi: 10.1002/1878-0261.12447. Epub 2019 Feb 2. PMID: 30657633; PMCID: PMC6396377.

² Dal Maso, L., Panato, C., Guzzinati, S., Serraino, D., Francisci, S., Botta, L., Capocaccia, R., Tavilla, A., Gigli, A., Crocetti, E., Rugge, M., Tagliabue, G., Filiberti, R., Carrozzi, G., Michiara, M., Ferretti, S., Cesaraccio, R., Tumino, R., Falcini, F., Stracci, F., Torrisi, A., Mazzoleni, G., Fusco, M., Rosso, S., Tisano, F., Fanetti, A., Sini, G., Buzzoni, C. and De Angelis, R. (2019). Prognosis and cure of long-term cancer survivors: A population-based estimation. *Cancer Medicine*, 8(9), pp.4497-4507.

ECPC will also ensure to:

- Push the implementation of the survivorship care in National Cancer Plans of the Member States
- Raise the issues of survivorship care in the Mission on Cancer
- To improve the quality of life of cancer survivors
- To raise awareness among policy makers and relevant stakeholders on the challenges that a cancer survivor faces during and after treatment

Actions

- Organisation of workshops to disseminate the Guide
- Publication of a series of factsheets for policy makers, cancer patients and cancer carers based on the content of the Guide
- Guide for patient organisations to drive survivorship care implementation in national cancer plans and cancer care practice at national level

Timeframe and Milestones

Month 1-3 Identification of countries where workshops will take place

Month 3-9 Organisation of the workshops

Month 1-6 Elaboration of the factsheets

Month 6-7 launch of the fact sheets

Month 7-9 translation of the factsheets in different EU languages

Month 3-12 update of the Guide

Deliverables

- Workshops on the Patient Guide on Survivorship
- Two factsheets based on the content of the Patient Guide on Survivorship
- Factsheets translated into 3 EU Languages
- Draft updated Guide

2.5 Social Disparities in Europe

Duration: January – December 2020

Context

The European Cancer Patient Coalition continues to lead an EU-level campaign towards greater equality in social and employment matters related to cancer care. As social issues and discrimination are one of the European competencies, there is a great opportunity for meaningful impact for all those affected by cancer. In 2017, ECPC published a White Paper on Cancer Carers intending to find the right societal response to give people with cancer and their carers a proper quality of life. Some of the key policy recommendations driven by ECPC have not come into law via the Work-Life Balance Directive, and there are further opportunities for improvement at national level. Throughout 2018 and 2019, ECPC carried out a survey to collect data on the existing benefits and legal provisions concerning employment, early retirement, sickness benefits and other social benefits for cancer patients and survivors. By building our knowledge on the current state of a range of social and employment matters in each Member State, ECPC has identified policy recommendations with a strong evidence base developed into a White Paper on Social Disparities in Europe. The White Paper includes recommendations which will be presented at an event in February 2020 and put forward throughout the year 2020.

Objectives

Building on the White Paper on Social Disparities in Europe in 2020 ECPC aims to facilitate policy change in social and employment laws across individual Member States and to support the implementation of changes into national cancer plans.

Actions

Specific Actions will include: the launch event, Meetings with relevant stakeholders at EU and Country level, Dissemination of the White Paper, Development of the Guide to support the implementation at country level of the White Paper recommendations, Identification of interested members, Translation of the White paper and the Guide in selected languages, Support to members on the implementation of the White Paper recommendations through webinars and/or workshops.

Timeframe and Milestones

Month 1-3 Dissemination of the white paper with ad hoc initiatives among our members

Month 1-6 Development of a Guide to support the implementation at country level of the White Paper recommendations

Month 2-5 Identification of members interested in receiving tailored support to the implementation of the White Paper recommendations in their countries

Month 3-6 Translation of the White Paper in selected languages

Month 6 Translation of the Guide in selected languages

Month 6 Workshop during ECPC annual congress

Month 4-11 Support to ECPC members through Workshops and/or webinars

Month 12 Report on the results achieved

Deliverables

- Meetings with relevant authorities to present the White Paper on Social Disparities at EU and national level report
- Workshop at the Annual Congress 2020 to widely disseminate the White Paper on Social Disparities and defining strategies to implement the recommendations
- Translations of the White Paper on Social Disparities in several languages (n. to be defined based on members interest)
- Guide on the implementation of the White paper recommendations at country level
- Translations of the Guide in several languages (n. to be defined based on members interest)
- Workshops and webinars reports
- Final report

2.6 Supporting Cancer Carers in Europe

Duration: January – December 2020

Context

The White Paper on Cancer Carers published by ECPC in 2017 in partnership with Eurocarers aims to find the right societal response to provide carers with support for a proper quality of life. ECPC advocacy action on the Work-Life Balance Directive for Parents and Carers achieved the formal recognition of carers and guarantees baseline support for informal caregivers across the EU. In particular, ECPC advocates to reinforce the formal recognition of carers and to introduce minimum standards for paid carers' leave and flexible working arrangements. A challenge remains to ensure that through the implementation of the Directive, cancer carers are not neglected, or even excluded from concrete support mechanisms set out in the law. As the urgency to support the carers who are caring for someone with a disability is paramount, it is important that cancer carers are not left behind.

Objectives

As the Work-Life Balance Directive enters the implementation phase, it is even more important to empower patient organisations in the Member States with the knowledge to monitor appropriate implementation and drive further support and rights for cancer carers in their countries. Providing concrete non-financial support mechanisms and social benefits for cancer caregivers is crucial. Member States should increase the number of days offered in cancer carers leave as part of Work-Life Balance Directive when implementing the Directive nationally. ECPC calls for greater protection on pension accrual, additional vacation time, flexible work arrangements and ease of transition from full-time to part time and other types of recovery of loss or limitation of employment due to caregiving. It is also fundamental to build a better understanding at which steps of the cancer care pathway caregiving becomes essential to support cancer carers and cancer patients in need of care. One of the steps to be considered for instance, the moment a patient is assigned home care, the caregiver is essential as otherwise home care cannot be delivered. It is important to identify these critical steps in cancer care pathway. Due to the risk of cancer carers being excluded from support and adequate compensation, ECPC aims to use this evidence to showcase the critical importance of carers in specific steps of cancer patients care pathway.

Actions

ECPC will provide guidance and support for member patient organisations to monitor the implementation of the Work-Life Balance Directive in the Member States through the development of a Guide and the organisation of workshops and webinars to support its implementation. ECPC will establish a platform of experts from different fields involved in cancer care pathway, to gather evidence and understanding when the specific role of a caregiver is essential in the different steps of the cancer patient care pathway, to provide a strong evidence-base for policymakers at a national level in order to support cancer carers.

Timeframe and Milestones

Month 1-6 Development of the Guide for the Work-Life Balance Directive

Month 6-12 Translation of the Guide into selected languages and dissemination of the Guide through ECPC communication media

Month 6-9-12 Organisation of Workshops and Webinars

Month 1-3 Design of the study on caregiver role in the cancer pathway

Month 3-10 Implementation of the study

Month 12 Launch of the study

Deliverables

- Guide for ECPC members to advocate for adequate implementation of the Work-Life Balance Directive
- Report on caregiver role in cancer care pathway
- Workshop at the Annual Congress 2020 on utilising the guide for advocacy at national level
- Workshops and webinars reports

2.7 Personalised Medicine

Duration: January – December 2020

Context

Each year, over 3 million people are diagnosed with cancer in Europe. 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 cancer molecular cancer testing and personalised medicine, a targeted approach to the prevention, diagnosis and treatment of cancer. Awareness about cancer molecular testing 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.

Objectives

In 2018, ECPC has launched the first-ever Personalised Medicine Awareness Month in November and will continue a third pan-European campaign in 2020. Organised in partnership with the European Alliance for Personalised Medicine (EAPM) and the International Quality Network for Pathology (IQN-Path), the awareness month aims to bring about new conversations on diagnostic and treatment options to European citizens and drive change for enabling policy and regulatory environments, as well as raise awareness among patients and decision-makers. In its third year, ECPC will partner with IQN-Path to deliver patient information material to address the main questions on Precision Medicine that come from patients and their families using a simple language.

Actions

In its third year, ECPC will work on delivering more in-depth information yet easy-to-understand patient information, engage with experts and policymakers to drive concrete policy recommendations stemming from policy discussion in the European Parliament in 2018. ECPC will also partner with IQN-Path to better understand the situation in the Member States on quality of biomarker testing and access in Europe. As a partner in the Innovative Partnership for Action Against Cancer (iPAAC) ECPC will use the experience and the outcomes of the joint action to support a paradigm shift on the use of genomics.

Timeframe and Milestones

Month 1-10 Planning and organisation of the Campaign

Month 11 Implementation of the Campaign

Month 3-9 Development of the campaign toolkit

Month 2-9 Development of the report on the quality of biomarker testing and access in Europe

Month 2-11 Development of the Patient Education Booklet on Personalised Medicine

Month 12 Launch of the Booklet

Deliverables

- Pan-European Awareness Campaign
- Campaign toolkit for ECPC member patient organisations to run campaigns at national level
- Translation of the toolkit in selected languages (n. to be identified)
- Report on Quality of biomarker testing and access in Europe delivered by IQN-Path in partnership with ECPC
- Patient Education Booklet on Personalised Medicine

2.8 Right to be forgotten

Duration: January – December 2021 (2 Years)

Context

Today, about half of patients who are diagnosed with cancer will survive for 10 years or more. There are currently over 14 million cancer survivors in Europe and the proportion of people predicted to survive the diagnosis of cancer is increasing by around 3% per year. Despite these increasing numbers, almost all EU countries lack adequate policies to ensure smooth reintegration of cancer survivors into social and professional life. Cancer survivors face a plethora of challenges to adjust and reintegrate as active members of society, yet even decades of being cancer-free and totally cured (patients who can be considered “cured”, as they have reached the same death rates of the general population³), survivors face discrimination in access to financial services which prevents them from travel, to secure a health insurance and to obtain a mortgage to own a home. France has set an example in Europe, by introducing the “Right to be Forgotten” law in 2016, not to declare their cancer 10 years after the end of the active treatment and 5 years if they had cancer under 18. In April 2019, Belgium has joined France as the second country in the EU to protect cancer survivors in statute from unfair treatment in relation to accessing financial services.

Objectives

It is important to gain on the momentum to continue the work based on the good examples of France and Belgium and strengthen the evidence-based advocacy efforts at the EU level and in individual Member States (MSs) to deliver the “Right to be Forgotten” universally across Europe. The “Right to be Forgotten” project will enable the European Cancer Patient Coalition to build a strong evidence base to actively drive advocacy to enhance policy measures with European institutions and Member States’ governments to overcome social disparities following best practice from France and Belgium and end discriminatory practices in financial services faced by cancer survivors in Europe.

Actions

The entire project will be conducted under the scientific supervision of Dr Françoise Meunier, Vice-President of the Federation of European Academies of Medicine (FEAM), who initiated the research and advocacy in this field over 5 years ago. Dr Meunier will act as a Scientific Leader of this project. ECPC will develop a precise map of existing regulations, policy or laws of same or similar kind in all EU Member States and identify the legislative needs to address discrimination of cancer survivors in financial services through desk research and surveys. This evidence will enable ECPC and its member patient organisations to pressure European institutions and Member States

³ Dal Maso, L., Panato, C., Guzzinati, S., Serraino, D., Francisci, S., Botta, L., Capocaccia, R., Tavilla, A., Gigli, A., Crocetti, E., Ruge, M., Tagliabue, G., Filiberti, R., Carrozzi, G., Michiara, M., Ferretti, S., Cesaraccio, R., Tumino, R., Falcini, F., Stracci, F., Torrisi, A., Mazzoleni, G., Fusco, M., Rosso, S., Tisano, F., Fanetti, A., Sini, G., Buzzoni, C. and De Angelis, R. (2019). Prognosis and cure of long-term cancer survivors: A population-based estimation. *Cancer Medicine*, 8(9), pp.4497-4507.

governments to introduce “Right to be Forgotten” legislation. Priority will be given to the development of a legislation in Italy where a memorandum of understanding has already been signed between insurance companies, tumour registries and the national cancer patient organisation FAVO to use the epidemiological evidence to convince policymakers about the importance to protect cancer survivors from any form of discrimination, including financial discrimination.

Timeframe and Milestones

Month 1 kick-off of the project

Month 1-10 Development of the study

Month 10-12 Development of the White Paper and recommendations

Month 13 Launch of the White Paper

Month 10-14 Development of the policy and advocacy engagement strategy

Month 10-22 Targeted support to the implementation of the law in Italy

Month 13-16 Translation of the white paper into selected languages (n. to be defined)

Month 14-24 Dissemination of the White Paper at EU and Country level

Month 6-18 Workshops at ECPC Annual Congress

Deliverables

- White Paper/Report “Right to be Forgotten”
- Policy and Advocacy engagement strategy to utilise the white paper for policy change
- Translations of the report
- Workshops at ECPC Annual Congress

2.9 CAR-T Treatments

Duration: January – December 2020

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 anew 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 through the dissemination of fact sheets and the organisations of webinars on the positive outcomes of CAR Ts to patients.

Objectives

Cancer patients 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 need to know more about the potential of these 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 personalized 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 personalized treatments and the need of patients and families to get trustworthy answers from experts to questions around the CAR T treatments, aims to:

- Convene an expert group of patients, clinicians, industry representatives, geneticists, and other experts to delineate the access problems from the patient perspective
- Publish a White Paper aiming to inform cancer patients about CAR T available treatments and research in this area.
- Translate the White Paper into selected languages (n. of languages to be defined)

- Organize a workshop 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.

Timeframe and Milestones

Month 1 Identification of a clear role for ECPC within the CAR T Platform

Month 1-3 Finalisation of the platform and elaboration of a Mission Statement

Month 2-6 Elaboration of a White Paper with recommendations

Month 6 Workshop on CAR T at ECPC Annual Congress and finalisation of the White Paper

Month 7 Launch of the White Paper with an event at the EU Parliament

Month 6-9 Translation of the White Paper

Month 10-12 Identification of ECPC members interested in receiving support for the following year

Deliverables

- Expert group/platform to collaborate with ECPC Scientific Committee for policy recommendations on CAR T treatments
- White Paper on CAR T treatments, aiming to inform patients about the scope, benefits and risks of CAR T treatments, latest treatments, cancer centers delivering them, and other useful information
- Workshop to present the White Paper and debate about the policy issues surrounding CAR T treatments.
- Report on CAR T Workshop
- Translations of the White Paper
- Activity Plan for the following year for ad hoc countries

2.10 Cancer Mission Europe

Duration: January – December 2020

Cancer Missions' Definition⁴

- Missions mean the mixing of issues from cancer research through to challenges faced in the Member States due to cancer.
- Mission-oriented innovation policy should shift the attention from R&D inputs to the full impact of the many complex systemic interactions between basic and applied research, development, innovation and the various accompanying spillovers.
- Missions are broader than sectors but more specific than challenges.
- Missions include European values such as equality, solidarity, public education and health care, security and social welfare.
- Missions require more focus on bottom-up experimentation and inter-disciplinarity.
- Missions should engage the society, patients, survivors, by making it clear that bold, inspirational actions at European level will develop solutions which will have an impact on people's daily life, whether he or she is a patient or not.
- Missions must link bold approach to what matters to the public, the sustainability of healthcare systems, inequalities and health and wellbeing.
- Missions should be framed in such a way as to spark activity across, and among, multiple disciplines in science, but also across different sectors (health, employment, social, services) and different types of actors (public, private, civil society and patient organisations)

Context

The increasing cancer burden is one of the leading medical and societal challenges today. Fighting cancer using a mission approach is highly likely to change the lives of many families across Europe, but also beyond the borders of the EU.

ECPC engaged very early in the debate about the mission-oriented approach to cancer and has collaborated closely, for more than two years now, with Cancer Core Europe and the prominent European Academy for Cancer Sciences (EACS), both within the Governing Body and the Science Policy Committee.

In order to rethink the strategies to combat cancer and to avoid the enormous dispersion of research funding that has not contributed to solving the problem of

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⁴"Mission-oriented Research & Innovation in the European Union", European Commission, Mariana Mazzucato, February 2018



cancer in contrast to other diseases, about 60 participants of the global oncology community, including the then ECPC President, Francesco de Lorenzo, met in The Vatican in November 2018. The meeting to discuss a mission-oriented approach to cancer in Europe was organised by EACS and the Pontifical Academy of Sciences. It was a key starting point for generating and contributing ideas to the framework and functioning of the Cancer Mission Europe.

As many as 13 million patients will be long-term survivors in 2035, in need of professional and social support and demanding continuous research efforts, especially in order to facilitate full reintegration into society in all aspects. ECPC, as a voice of cancer patients in Europe, has taken

a prominent role in high-level discussions on Cancer Mission Europe and will continue to engage with the oncology community and the European Commission in 2020, and beyond, on the basis of the principle of “Science with and for Society”.

To date, several prominent scientific cancer organisations and cancer centres are collaborating to develop a unified insight towards a mission-oriented approach to cancer. These include Cancer Core Europe, Cancer Prevention Europe, the Organisation of European Cancer Institutes (OEI), the European Organisation for Research and Treatment of Cancer (EORTC), the European Association for Cancer Research (EACR), the EURO Tech University Alliance, the ECPC, the EACS and other organisations are expected to join shortly.

The EACS, as an independent organisation, composed of eminent oncologists and cancer researchers, has actively supported the concept of a Cancer Mission and as a result, has been requested to coordinate the process of developing such a joint strategy to speak with a single voice.

The special issue of Molecular Oncology, published on March 1st this year – featuring the ECPC’s perspective “The European Cancer Patient Coalition and its central role in connecting stakeholders to advance patient-centric solutions in the mission on cancer” - presents the views of key members supporting the mission-oriented approach to cancer.

ECPC strongly advocates for considering the Cancer Mission as a mix of challenges from research to social, economic and welfare issues in Member States. ECPC Past-President and Chair of the Scientific Committee represents the organisation and thus the interests of cancer patients as a Member of the Board and of the Science Policy Committee of EACS.

The aim of the CANCER MISSION is 1) to increase the 10-year survival of European cancer patients to 75% by 2030 (by improving early diagnosis and treatment), and 2) to reduce the age-corrected cancer incidence through primary prevention in the subsequent ten years by 20%.

Objectives

ECPC believes that the mission-oriented approach to cancer will offer the opportunity to tackle the disease also as a social issue, based on science for and with society, involving not only patients, families and caregivers, the medical and research communities and policymakers, but also society at large.

Objectives of ECPC involvement on the cancer mission are the following:

- To guarantee that the voice of cancer patients, survivors and carers is heard by the scientific and policymakers community
- To advocate with Board Mission and EU institutions on cancer patients, survivors and carers interest
- To collaborate among all the stakeholders (basic researchers, clinical oncologists/healthcare professionals, pathologists, radiation oncologists, surgeons, prevention researches, epidemiologists, patients, universities, industry and SMEs, regulatory bodies and funders)
- To involve cancer research, prevention/health care and cancer patient communities at all stages of policymaking
- To move towards evidence-based predictive and personalized cancer medicine which includes health-related quality of life research, psychosocial oncology, rehabilitation, supportive and palliative care, long-term follow-up and survivorship research, health economics including social consequences of a cancer diagnosis.

ECPC's position on Mission on Cancer is described in the review article: "The European Cancer Patient Coalition and its central role in connecting stakeholders to advance patient-centric solutions in the mission on cancer"- F. De Lorenzo and K. Apostolidis, published on February 2019 in a Special Issue of Molecular Oncology.

Actions

ECPC will actively contribute through EACS and in partnership with leaders in the oncology community gathered by EACS, to provide guidance and support to the Chair of the Mission Board on Cancer.

Specific actions include:

- Information to ECPC members and the cancer patient community at large on the cancer mission opportunity through fact sheets, articles on the newsletter, social media outreach

- Gather challenges and needs from the cancer patient community through Facebook live sessions
- Participation into high-level scientific platforms such as EACS board and all the other scientific platforms, such as CCE, CPE, OECl, EORTC and the EURO Tech University Alliance

Timeframe/milestones

Month 1-3 Development of fact sheets

Month 4-12 Translation and dissemination of fact sheets in selected languages

Month 1-12 Meeting with relevant scientific platforms and policy makers, whenever needed

Month 1-6 Organisation of 2 Facebook live sessions

Deliverables

- Fact sheets on the cancer mission approach and priorities identified for ECPC members
- Translation of the Fact sheets
- Meeting reports, whenever possible due to restricted meeting policy

Another EU Missed Opportunity: cancer mission with no patient on board?

The European Commission, after first communicating the name of the Chair of the cancer mission, last week announced the 15 experts selected as members of the Horizon Europe cancer mission board. Contrary to expectations, no cancer patient representative was selected. *“The European Cancer Patient Coalition (ECPC) is surprised that the value and importance of patient input have not been recognized”,* stated Kathi Apostolidis, President of ECPC.

This is particularly surprising in the light of the European Commission’s second cancer mission report ‘Governing Missions in the European Union’ where dedication to citizen engagement, reinforcement of its transparency and legitimacy are described as the ultimate level of a robust public trust ensuring longevity to the mission and adoption of its conclusions.

ECPC believes that the mission-oriented approach to cancer will offer the opportunity to face cancer also as a social issue, based on science for and with society, involving not only patients, families and carers, the medical and research communities, policymakers but also society at large. ECPC was very early interested in the debate about the mission-oriented approach to cancer and collaborates closely, for more than

two years now, with the eminent European Academy for Cancer Sciences-EACS within the dialogue platform established by EACS.

Under the guidance of EACS, besides ECPC, the following well-known scientific cancer organizations, among several other, collaborate in the platform: Cancer Core Europe, Cancer Prevention Europe, OEI, EACR, EORTC. EACS, as the platform leader, takes care that the perspectives of all participants are reflected in the works and documents of the platform. The special issue of Molecular Oncology, published on March 1st, featuring ECPC's perspective "The European Cancer Patient Coalition and its central role in connecting stakeholders to advance patient-centric solutions in the mission on cancer", presents the views of key members of the EACS platform on the mission-oriented approach to cancer.

With three million people being diagnosed with cancer each year, the complexity of the disease means we are facing a global issue, highlighting the critical need to organically connect cancer research to cancer and survivorship care to solve the burden of cancer: *"survivorship, fighting inequalities in access to care, to surgery, removing the stigma facing patients and survivors, getting the growing ranks of survivors back to work and caring for the cancer patient"*, were listed by Francesco De Lorenzo, Chair of the Scientific Committee of ECPC, in an article of Politico Pro published on Aug. 4, 2019. Without tackling these social aspects of cancer within the cancer care continuum, the cancer mission will be looking at just a part of the cancer burden. Patients insights will enrich and strengthen the value of a patient-centric, societal approach to the cancer mission.

The EU Joint Actions for Cancer (EPAAC, CanCon, iPAAC, JARC, ECIBC) in which the Commission took care to include the patient perspective on equal terms as that of all other participants, and in which, namely in CanCon, ECPC, representing cancer patients, had its policy proposal accepted by 17 Member States and co-authored Joint Action policy papers, should be the beacon guiding also the cancer mission. ECPC has participated in all Joint Actions for cancer, and it has considerably contributed to the Joint Action on Cancer Control (CanCon), establishing, among others, the importance of survivorship in National Cancer Plans of Member States. Providing crucial knowledge and policy recommendations from the perspective of the patient, is just one example of achieving a broader perspective on the cancer mission, creating more cohesive policy that addresses cancer research, evidence-based predictive and personalized cancer medicine including health-related quality of life research, psychosocial oncology, rehabilitation, supportive and palliative care, long-term follow-up and survivorship research, health economics including social consequences of cancer and employment issues.

"We look forward to building a constructive and collaborative relationship with the Chair and the chosen experts of the cancer mission, as we already do more than a year ago with the renown experts of the EACS cancer mission platform and we have done till now in the Joint Actions for cancer. Such collaboration will only enrich and broaden the scope of cancer research and care through combatting disparities and inefficiencies together", said Kathi Apostolidis, President of ECPC.

As promised in its mandate, ECPC will continue its mission to overcome the inequalities in cancer care and strive to ensure that cancer patients are considered by decision-makers as co-creators of their health.

3. Health and Research

3.1 EURACAN

Full name

European Reference on Rare Adult Solid Cancer (ERN-EURACAN)

Type of Action

European Reference Network - Cancer

Funding



EURACAN is one of the 24 European Reference Networks (ERNs), approved by the ERN Board of Member States, funded by the EU's [3rd Health Programme](#)

Project Duration 01/03/2017 – 28/02/2022 (5 years)

Lead Coordinator Centre Léon Bérard

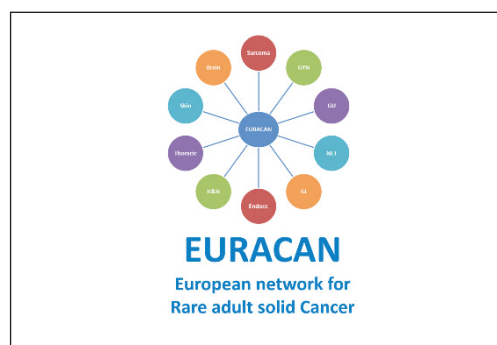
Website: <http://euracan.ern-net.eu/>

Context

There are more than 4 million people affected by rare cancers in the EU, representing about 24% of all cancer cases diagnosed in the 28 Member States each year. Rare cancers are identified as those with an incidence of less than 6 per 100,000 persons per year. [European Reference Network \(ERN\)](#) on Rare Adult Solid Cancers (EURACAN) is a network connecting health care providers and centres of expertise of highly specialised healthcare, for the purpose of improving access to diagnosis, treatment and the provision of high-quality healthcare for rare adult solid cancer patients in Europe. EURACAN distinguishes rare cancers into **10 domains** corresponding to the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD10) and RARECARE.

Objectives

EURACAN specifically aims at increasing and accelerating access to pathological diagnosis and associated treatments across all EU Member States with a view of improving patients' quality of life and survival rates, developing dedicated medical training programmes covering the whole range of Rare Adult Cancer, in order to increase and harmonise the quality of care, the wide dissemination of educational tools for rare adult cancer physicians



and patients, implementing “roadmaps” for referral and self-referral of patient to expert centres, to optimize patients’ care pathways and ultimately quality of care, developing and continuously reviewing clinical practice guidelines across the various domains, to spread and homogenize best practices, and carrying out a thorough socio-economic assessment of the impact of Rare Adult Cancer on patients quality of life and healthcare systems, formulating recommendations.

ECPC Actions

ECPC is an **elected European Patient Advocacy Group member (ePAG)** representing rare adult solid cancer patients across the 10 rare cancer domains and it participates in the EURACAN Board and Steering Committee. ECPC **co-leads Dissemination and Communication** activities and is part of the EURACAN Task Force on research. ECPC counts on the expertise and collaboration of rare cancer patient organisations all over Europe to continuously represent the rare cancer patient community.

Timeframe and Milestones

Month 1 – 12 Exchange of best practices with labelled ERN representatives to avoid duplication of effort

Month 2 Annual communication plan

Month 1 – 11 Updated EURACAN leaflets

Month 6 – 8 EURACAN Newsletters

Month 11 Training/Education workshops

Deliverables

- Harmonised Clinical Practice Guidelines publication on the EURACAN website
- EURACAN patient multidisciplinary management pathway
- Communication and dissemination report
- Exploitation plan
- Training/Education tools

3.2 LEGAcy

Full name

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



Type of Action

RIA (Research and Innovation Action)

Funding



LEGACy is funded by the EU Horizon 2020 Research and Innovation Programme.

Project Duration 01/01/2019 – 31/12/2022 (4 years)

Lead Coordinator

INCLIVA Health Research Institute

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

Context

Gastric cancer is the third leading cause of cancer death in both sexes worldwide and no strategies have improved prognosis in locally advanced gastric cancer. An increase in survival rate for patients with gastric cancer is expected to come from a personalized medicine approach. So far, gastric cancer treatments such as surgery, radiotherapy, chemotherapy or immunotherapy were used. While these treatments might work for one person, this does not mean they will work for another, despite the possible side effects. Through personalized medicine, gastric cancer treatment is chosen, based on who the patient is, instead of the type of tumour, leading to an improved prognosis of gastric cancer.

Objectives

LEGACy aims to use a personalized 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.

ECPC Actions

ECPC leads the project's work on Communication and Dissemination, ensuring an effective external stakeholder network, and 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.

Timelines and Milestones

- Month 4, 8 and 12 Newsletters

- Month 1 – 12 Website maintenance
- Month 1 – 12 Communication and Dissemination Activities

Deliverables

- Newsletters
- Annual Social Media Report

3.3 DIAdIC

Full name

Dyadic Psychosocial and Educational Interventions for People with Advanced Cancer and their Informal Caregivers (DIAdIC)



Type of Action

RIA (Research and Innovation)

Funding



DIAdIC is funded by the EU Horizon 2020 Research and Innovation Programme.

Project Duration 01/01/2019 – 31/12/2023 (5 years)

Lead Coordinator

Vrije Universiteit Brussel

Website: <https://diadic.eu/>

Context

A cancer diagnosis negatively impacts both the patients as well as the family caregiver. Good psychosocial and educational support can substantially reduce this impact and improve the quality of life of both.

Objectives

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.

ECPC Actions

ECPC leads on Dissemination and Communication activities, 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 to draft implementation guidelines for the DIAdIC interventions, to write a position paper with policy and awareness recommendations, and ECPC will host the final stakeholder event at the end of the project.

Timelines and Milestones

- Month 6 and 8 Newsletters
- Month 1 – 12 Website maintenance and social media activities
- Month 1 – 12 Communication and Dissemination Activities

Deliverables

- Annual Communication and Dissemination Report
- Newsletters

3.4 Palliative Sedation

Full name

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



Type of Action

RIA (Research and Innovation Action)

Funding



Palliative Sedation is funded by the EU Horizon 2020 Research and Innovation Programme.

Project Duration 01/01/2019 – 31/12/2023 (5 years)

Lead Coordinator

Radboud University Medical Centre

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

Context

Due to the rise in cancer and multiple chronic disease, the number of patients with refractory symptoms where conventional treatment options fail, is likely to increase. In such cases palliative sedation (PS) can be indicated which involves the intentional lowering of consciousness at the end of life. However, palliative sedation is too often restricted to continuous deep sedation and is often confused with hastening of death.

Objectives

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

ECPC Actions

ECPC sits on the Palliative Sedation (PS) Scientific, Clinical and Ethical Advisory Board advocating 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 the study is designed and adapted to better respond to patient needs. Through its Members, ECPC contributes to a PS country survey and to supportive interviews that reveal the level of integration of clinical sedation guideline recommendations in health care practice across Europe. ECPC also supports the revision of the current European Association for Palliative Care (EAPC) framework for palliative sedation, and the design of the palliative sedation educational programme and e-book containing clinical and ethical guidance that can be adopted for PS.

Timelines and Milestones

Month 12 Palliative sedation on line programme design

Deliverables

- Design of Palliative Sedation online programme

3.5 Denim

Full name

DENDritic cell-based immunotherapy to treat Malignant Mesothelioma H2020 (Denim)

Type of Action

RIA (Research and Innovation Action)

Funding



H2020MM04 Denim is funded by the EU Horizon 2020 Research and Innovation Programme.

Project Duration 01/01/2016 – 31/12/2019 (4 years) Extended to January 2021

Lead Coordinator

Erasmus University Medical Center Rotterdam

Website: <https://www.denimstudy.eu/>

Context

Asbestos is one of the major causes of work-related cancer. Although asbestos is banned, it is still present in many buildings across the European Union and millions of workers and consumers are still exposed to asbestos. Inhalation of even very low quantities of asbestos fibres tremendously increases the risk of developing malignant mesothelioma (MM), a rare cancer of the thin lining of the lung, chest wall and abdomen. MM is a rare but highly aggressive cancer that kills about 43,000 people worldwide every year. Despite EU action, mesothelioma incidence is still increasing. Unfortunately, there is no effective therapy, which makes it a highly fatal disease. Killing MM patients within a year from diagnosis.

Objectives

The H2020MM04 Denim project is further testing a promising personalised immunotherapy to treat MM with very limited side effects. The study is a randomised phase II/III clinical trial. First clinical results show a considerably prolonged average survival with limited adverse events. The EMA and the FDA



granted this therapy Orphan Designation (EU: 16 January 2014 - EU/3/13/1229; FDA – US: 06 May 2014).

ECPC Actions

ECPC enables H2020MM04 Denim to directly engage with expert patient representatives to ensure the study is designed and adapted to better respond to patient needs. Specifically, ECPC is leading a patient panel of ECPC members and other patient groups. ECPC collaborates in the organisation of the Denim educational days for patients and their caregivers, providing an easy consultable, layman-language source of information on H2020MM04 cancer therapy to patients and their caregivers, and effectively disseminating project news and results.

Timelines and Milestones

Due to several delays in the country approvals for the clinical studies, the actual study date has been postponed to June 2018 with a completion date of January 2021. An amendment has been initiated. The project is in its initial phases.

3.6 PREFER

Full name

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



prefer.
PATIENT PREFERENCES

Type of Action

RIA (Research and Innovation Action)

Funding



PREFER is funded by the Innovative Medicines Initiative (IMI) 2, as part of the EU Horizon 2020 Programme, and the European federation of Pharmaceutical Industries and Associations (EFPIA).

Project Duration 01/10/2016 – 30/09/2021 (5 years)

Lead Coordinator

Uppsala University

Website: www.imi-prefer.eu

Context

Industry, Regulatory Authorities, Health Technology Assessment (HTA)

bodies, reimbursement agencies, and patient organizations agree that patient preference is vital in all medical research and particularly in drug development, however there is little guidance on conducting and using such studies.

Objectives

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 give valuable information to support decision making and it identifies recommendations for the development of guidelines for Industry, Regulatory Authorities and HTA bodies on how and when to include patient perspectives on benefits and risks of medicinal products.

ECPC Actions

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. ECPC contributes to the overall project design, to set up patient focus groups, to review surveys, study protocols and guidelines, to communication and dissemination of 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.

Timelines and Milestones

Month 12 First draft of PREFER recommendations

Deliverables

- PREFER Sustainability Plan
- PREFER Workshop on preliminary results
- Report on lung cancer case study
- Report describing the requirements for patient-preference elicitation case studies to inform benefit-risk decisions

3.7 BD4BO PIONEER

Full name

Prostate Cancer diagnosis and treatment enhancement through the power of Big data in Europe (PIONEER)



Type of Action

RIA (Research and Innovation Action)

Funding



PIONEER is funded by the Innovative Medicines Initiative (IMI) 2, set up under the **Big Data for Better Outcomes (BD4BO)**, part of the EU Horizon 2020 Programme, and the European federation of Pharmaceutical Industries and Associations (EFPIA).

Project Duration 01/05/2018 – 30/04/2023 (5 years)

Lead Coordinator University of Aberdeen

Website: www.prostate-pioneer.eu

Context

Prostate cancer (PCa) is the second leading cause of cancer in men, accounting for **9% of all cancer deaths among men in Europe**. The socio-economic burden associated with it is predicted to dramatically increase in the coming years due to aging. Currently, it is hard to predict which patients will respond best to different treatments, and which patients can be managed safely without undergoing treatment. PIONEER is one of the BD4BO disease-specific projects and serves as the European Network of Excellence for Big Data in Prostate Cancer.

Objectives

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.

ECPC Actions

ECPC provides expert patient input and advice during the entire life cycle of the project. The participation of ECPC ensures the patients engagement with their disease management, thus leading to better treatment adherence and improved Quality of Life (QoL). ECPC's tasks within the project include reviewing informed consent forms, surveys, study protocols and guidelines, setting patient focus groups, drafting patient information leaflets and brochures, and communication and dissemination of project's deliverables. ECPC also ensures 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.

Timelines and Milestones

Month 12 Report on dissemination and communication strategy and updates

Deliverables

- Online website updates and translations

3.8 Immune Image

Full name

Specific Imaging of Immune Cell Dynamics Using Novel Tracer Strategies

Type of Action

RIA (Research and Innovation)

Funding



Immune Image is funded by the EU Horizon 2020 Research and Innovation Programme.

Project Duration 01/10/2019 – 30/09/2024 (5 years)

Lead Coordinator VU University Medical Center

Context

Immunotherapies have become one of the most effective treatment options in cancer. However, variations between patients limit the use and success of immunotherapies. To improve patient response, a personalised medicine approach needs to be applied where the treatment is chosen on an individual basis and continuously guided to adapt to changes.

As the efficiency of immunotherapies depends on drug response, careful selection and monitoring is extremely important. Immune-Image will focus on developing and implementing non-invasive molecular imaging technologies for assessing immune cell response, aimed to guide this selection and monitoring.

Immune-Image will develop, optimise and validate existing and novel cell-specific immune imaging techniques, establish imaging protocols, workflows and software, and prepare the regulatory framework for clinical trials using novel immune imaging approaches for developing, selecting and monitoring immunotherapies.



ECPC Actions

Immune-Image will actively involve patients to gather their concerns and recommendations regarding the use of the project's diagnostic approaches, treatment outcomes and quality of life.

ECPC leads the dedicated communication team of Immune-Image and governs dissemination to patient organisations, including incorporation of Immune-Image in Personalised Medicine Awareness Month campaigns and sharing Immune-Image through ECPC's media channels and presentations. ECPC sits on the Ethics & Privacy Advisory Board (EAB), an independent consultant body for the management of the consortium.

Timelines and Milestones

Month 1 – 12 – Communication activities and dissemination to patient organisations

Month 3 – Communication plan

Month 3 – Public website

Deliverables

- Communication Plan

3.9 Scientific Committee and Advisory Role

ECPC sits on several Scientific Committee and Advisory Boards to ensure that the cancer patients voice is heard. ECPC monitors projects' progress and provide input on the design and overall direction. ECPC also uses its communication channels to share information about, various projects, interim and final results.

3.10 Transcan-2

Full name

ERA-NET: Aligning national/regional translational cancer research programmes and activities (Transcan-2)

Type of Action

ERA-NET (European Research Area)



Funding



Transcan-2 is funded by the EU Horizon 2020 Research and Innovation Programme.

Project Duration 01/01/2011 – 31/12/2020 (6 years)

Lead Coordinator Italian Ministry of Health

Website: <http://www.transcanfp7.eu/>

The project in brief

Cancer is a worldwide health burden and represents a major public health challenge in Europe. Today, an estimated 9 million individuals in Europe live with cancer contributing to the ongoing increase in medical expenditures, and accordingly poses a major socio-economic challenge in the EU. Translational research applies knowledge from basic biology and clinical trials to techniques and tools that address critical medical needs to reduce cancer incidence and mortality rates, improve the quality of life of patients, and overall health outcomes. TRANSCAN-2 aligns national and regional translational cancer research programmes and activities to link translational cancer research funding programmes. This avoids duplication of efforts and ensures more efficient use of available resources.

ECPC Actions

The Scientific Advisory Board meets once annually and its main task is to reflect on the program's strategy, to decide, write and review the calls for expression of interest to participate in Transcan 2 funded projects, make recommendations to the Commission and national governments regarding the project. ECPC is represented in the SAB for the last three years by its President.

3.11 ELBA

Full name

European Liquid Biopsies Academy
- Towards widespread clinical
application of blood-based diagnostic
tools (ELBA)

Type of Action

ITN (Innovative Training Network)

Funding



ELBA is funded by the Marie Skłodowska-Curie Actions, part of the EU Horizon 2020 Programme.



Project Duration 01/01/2018 – 31/12/2021 (4 years)

Lead Coordinator VU University Medical Center

Website: <https://elba.uni-plovdiv.bg/>

The project in brief

During a tissue biopsy a sample of cells is removed from the body to determine the presence, cause or extent of cancer. Liquid biopsies are blood tests offering a minimally invasive, safe, and sensitive alternative or complimentary approach to tissue biopsies. However, the development and commercialization of liquid biopsy approaches is currently hampered by various obstacles.

ELBA will educate 15 Early Stage Researchers with the skills to face these obstacles in key disciplines of molecular biology and medicine, bioinformatics, biostatics, 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 to liquid biopsy test development.

ECPC Actions

ECPC provides the Early Stage Researchers 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.

3.12 PREDICT

Full name

A new era in personalised medicine: Radiomics as decision support tool for diagnostics and theragnostics in oncology (PREDICT)

Type of Action

ITN (Innovative Training Network)

Funding



Predict is funded by the Marie Skłodowska-Curie Actions, part of the EU Horizon 2020 Programme



Project Duration 01/10/2017 – 30/09/2021 (4 years)

Lead Coordinator Maastricht University

Website: <http://predict-itn.eu/>

The project in brief

Tumour cells can differ greatly both between patients (inter-tumour heterogeneity) and within patients (intra-tumour heterogeneity). These differences affect how patients respond to cancer therapy and hampers wide deployment of personalised medicine for cancer treatment. PREDICT educates 15 Early Stage Researcher (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.

ECPC Actions

ECPC provides the Early Stage Researchers 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.

3.13 EUCANCan

Full name

Federated network of aligned and interoperable infrastructures for the homogeneous analysis, management and sharing of genomic oncology data for Personalized Medicine (EUCANCan)



Type of Action

RIA (Research and Innovation)

Funding



EUCANCan has received funding from the European Union's Horizon 2020 research and innovation programme

Project duration 01/01/2019 – 31/12/2022 (4 years)

Lead Coordinator Barcelona National Supercomputing Center

Website: <https://eucanacan.com/>

The project in brief

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 personalized medicine initiatives, allowing the exchange of data, clinical experience and information across different national health systems.

New Proposals

The European Cancer Patient Coalition participates in projects **funded by** Research and Innovation framework programmes such as the [IMI 2, Horizon 2020 \(H2020\) and ITN programmes](#). As one of the few cancer patient organisations actively involved in EU-funded projects, ECPC will continue to **apply for funding and participating in new project proposals**.

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 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

- Drafting the questionnaire
- Testing it on ECPC Members and making the necessary adjustments
- Distributing it and collecting the answers
- Analysing the answers
- Reporting and addressing the findings

Timeframe and milestones

Month 1 Distribute an agreed questionnaire among all ECPC members

Month 3 Deadline to start analysing the questionnaire

Month 4 Report ready to be shared internally

Month 5-12 Suggested changes implemented

Deliverables

- Questionnaire
- Table summarizing the answers, including statistics and key words
- 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.

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
- Selection of a venue, organization of accommodation and logistics of the event
- 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

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

- Background information mailing
- Live Q&A video or webinar report
- AGM minutes

4.2.3 Guides

4.2.3.1 ESMO patients guides

Logo



Website <https://www.esmo.org/Patients/Patient-Guides>

Partners ESMO (European Society for Medical Oncology) with IPOS (International Psycho-Oncology Society)

Duration all year long, depending on ESMO calendar

Context

ECPC is directly involved in drafting updates of new ESMO Clinical Practice

Guidelines. ECPC and ESMO decided to partner so to include more patient-friendly and solid information in the guidelines. In the last years, each updated ESMO Guideline contained a reviewed, patient-oriented survivorship chapter. Simultaneously, ECPC published on its website all ESMO Guides for Patients. Most, but not all the work on the guidelines is referred to rare cancers. There are over 198 types of rare cancer, highlighting the need to help patients and their carers understand the characteristics of their cancer and the treatments available to them. Rare cancers require much research and patients deserving support and reliable information sources. There are currently 8 rare cancer guides available and we aim to continue this work.

Objectives

The Guides for Patients are designed to assist patients, their relatives and caregivers in better understanding the nature of different types of cancer and evaluating the best available treatment choices.

Actions

ESMO produces (writing, layout, printing, publishing online) information detailing the nature of specific rare cancers to assist patients, carers and relatives. These guides are written by experts, mainly health care professionals.

ECPC contributions

ECPC has been supporting ESMO's work for several years by providing them with the patient's perspective. ECPC will continue to involve its Members in the process of editing the content of each guide in order to check their accessibility for patients. In doing so, the right to information is guaranteed.

Deliverables

Topical patient guides, both digital and printed versions (A5 format, number of pages and number of hard copies vary)

4.2.3.2 ESMO Survivorship guide

Logo



Website <https://www.esmo.org/Patients/Patient-Guides>

Partners ESMO (European Society for Medical Oncology) with IPOS (International Psycho-Oncology Society)

Duration 10 months

Context

Survivorship focuses on health and the physical, psychological, social and economic issues facing patients at the end of their treatment for cancer. Surviving to cancer doesn't stop to the end of treatments anymore. ESMO, with ECPC, support developed a Cancer Survivorship Guide in several languages. ECPC is helping to disseminate the guide with different means and in different countries.

Objectives

To help disseminating the guide to patients and their carers in different Countries.

Actions

In the guide ESMO explores all the different aspects of survivorship and develops an innovative but easy-to-follow tool for patient to keep a personal health record and a survivorship plan.

ECPC contributions

- ECPC will organise events to launch the guide in Europe specifically dedicated to patients. Survivors will be invited to share their experience and experts will demonstrate the multiple facets of this complex topic. Involving attendees (survivors, patients, carers, health care professionals, researchers, journalists, social influencers, decision-makers, etc.) will be key to successfully present the survivorship plan.
- ECPC will support the translation of the guide in various European languages. Once they are finalised, ECPC will disseminate the guide through social media, on its website, during events and meetings.

Timeframe / milestones

Month 1-2 Agreement of a work plan with ESMO and partners

Month 2-12 Translation of the guide and dissemination

Month 3-11 Organisation of workshops and ad hoc events to disseminate the guide

Deliverables

- Translated and layout versions of the Survivorship guide
- Events

4.3 Awareness campaigns

4.3.1 *Bladder Cancer Awareness Month & Policy*

Logo



Website <http://www.ecpc.org/edu/bladder>

Partners Fight Bladder Cancer

Duration 5 months

Context

Bladder cancer is the fifth most common cancer in Europe and can affect everyone. There are 150 000 new cases each year in Europe. Only 1% of money spent on cancer research is spent on bladder cancer. Bladder cancer can often be overlooked by patients and General Practitioners due to symptoms often being associated with less serious, more common issues such as urinary infections. It is the only top 10 cancer whose prognosis is getting worse.

ECPC works on Bladder Cancer in close collaboration with the European Association of Urology (EAU). In fact, since 2018 the two organisations have formalised their partnership, that started in 2015, with a Memorandum of Understanding (MoU). As a follow up of this MoU, ECPC is a founding and active member of the newly established EAU Patient Advocacy Group (EPAG), that was launched in March 2019 at the EAU congress in Barcelona.

Objectives

- To promote awareness of this type of cancer and its symptoms towards the general public: early diagnosis is the biggest difference in beating this cancer
- To call for more investment in research

Actions

- Development of a range of tools, including a social media kit, branded graphic elements and infographics
- Share ideas on different activities and gatherings for patient organisations and individuals to get involved and do their bit for bladder cancer in their own way

- Organisation of a webinar to share information and guidelines on how to get involved and use the materials produced
- Promotion of the campaign towards Members, partners, decision-makers, media and general public

Timeframe / milestones

Month 3-4 Toolkit preparation

Month 3 Reaching Members and engaging with them

Month 4 Webinar

Month 5 Launch of the campaign and PR

Deliverables

- Campaign tool kit: update of the messages and the graphic design, new ideas of activities
- Dedicated page on ECPC website
- Calendar of promotional posts
- Press release and press article

4.3.2 *Make Sense of head and neck cancer campaign*

Logo



Website <https://makesensecampaign.eu/en/>

Past partners: EHNS (European Head and Neck Society)

Duration: 3 years

Context

Head and neck cancers are among the most common cancer types in Europe, with more than 150.000 new patients diagnosed each year. Despite being the 7th most common cancer worldwide, and each individual tumour being classified as a rare cancer, there is little awareness of this, with patient outcomes remaining poor for those diagnosed in the later stages. However, for those diagnosed in the early stage, there is an 80-90% survival rate.

Objectives

The Make Sense Campaign aims to raise awareness of head and neck cancer and ultimately improve the outcomes for patients with the disease. There needs to be more education surrounding the disease, earlier diagnosis and referral, and an overall improvement in the care of patients. The challenge is to communicate the complexities of head and neck cancers in a space where other cancers have wider recognition and understanding, ensuring better chances of survival.

Actions

In order to make a concrete difference EHNS has started to work on survivorship guidelines to head and neck cancer for healthcare professionals.

ECPC contributions

This new tool will be at the heart of an ambitious communication and advocacy campaign targeting Member States over the coming years. ECPC will oversee supporting national implementation of the guidelines.

Timeframe / milestones

2020: Getting ready with MEPs: using their expertise and insights to identify national specificities and to set up an action plan at national level.

2021: Targeting 3-5 “champion” Member States where the national action plan will be deployed with the help of MEPs, ECPC Members, partners and funders

2022: Targeting the remaining Member States

Deliverables

- Survivorship guidelines in EU for HCP
- Action Plans for 2020, 2021, 2022

4.4 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:
- Crowd funding
- Fundraising event: conference, sport event, charity sale, exhibition...
- Donations and legacy
- Legal obligations related to fundraising
- 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: September 2020, December 2020, April 2021, September 2021, December 2021

Month 1-12 Articles on best practices all year long

Deliverables

- Fact sheets
- Webinar report/s

4.5 Nutrition

Project Duration: 12 months

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 updated survey was developed in 2016**. It aimed to describe and understand the perception of the importance of metabolic and nutritional problems among patients and cancer survivors. A total of 907 patients and survivors were surveyed in 10 European countries including: Finland, Italy, Spain, Czech Republic, Greece, Denmark, Slovenia, Romania, Poland, and Bulgaria. The study illustrated a substantial gap in terms of need for information and practical management of cancer-related nutritional problems for people with cancer. This was presented at the 2017 Annual Meeting and the ESMO 2017 Congress with a featured abstract in the Congress Book, a supplement of the Annals of Oncology.

In November 2017, MEP Daciana Octavia Sârbu, in collaboration with ECPC, hosted an event in the European Parliament on the Role of Nutrition in Cancer Care to launch the "Living Well During Cancer Treatment" booklet. The booklet includes the results from the ECPC survey, "questions to ask your Oncologist", key messages, and a proposed Cancer Patient's Charter of Rights for Appropriate and Prompt Nutritional Support. The booklet was also officially endorsed by the European Society for Surgical Oncology (ESSO).

In March 2018, ECPC promoted the importance of nutrition and physical activity during a month-long advocacy campaign. ECPC also created the "Nutrition and Physical Activity Awareness Month Toolkit" to provide guidance to its Members on how to join and support the campaign. Communications materials were made available in ten different 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 carried on with the Cancer and Physical Activity Awareness Month in March and 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. ECPC is then committed to continue its collaboration with various stakeholders to ensure Nutrition is a priority on the EU agenda.

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 disseminated using social media, ECPC website and newsletter. The material will be also disseminated at any other relevant event ECPC is participating, such as ISPOR and ONCA conferences.

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 a Series II of the “Living Well during Cancer Treatment Nutrition Patient Booklet” addressing more specific cancer patient concerns.

Timeframe and Milestones

Month 1-3: Development of the Living Well Factsheets, Nutrition and Physical Activity Awareness Month

Month 6: “Living Well” Patient Factsheet translation and dissemination

Month 2-12: First Draft of Series II of the Living well During Cancer Treatment Nutrition Patient Booklet

Month 6-12: National Events

Deliverables

- “Living Well During Cancer Treatment” booklet printed into different languages
- “Living Well” Patient Factsheet available in 10 languages
- National events
- First Draft of Series II of the “Living well During Cancer Treatment Nutrition Patient Booklet”

4.6 Physical Activity

4.6.1 *Sport and Physical Activity for Cancer patients during and after treatment*

Duration: 24 months

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 treatments¹.

Already in 2012, several studies² 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 patient³. 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.⁴

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:

- Survey among ECPC member associations on the awareness of the effectiveness of physical exercise and sport during and after cancer to patients and caregivers
- Creation of an 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
- Organisation of an event at the European Parliament to sensitize policy makers

Timeframe and Milestones

Month 1-2 agreement with sponsors on an execution project

Month 2-3 development of the survey and dissemination of it

Month 4-5 analyses of the answers to the survey

Month 5-7 development of a booklet

Month 7-12 dissemination and awareness campaigns

Deliverables

- Survey analyses report
- Booklet to inform cancer patients, policy makers and health care professionals
- Communication plan
- Awareness campaigns reports

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2 [Weiner J](#). **Once a taboo, exercise becomes post-cancer-surgery rehab tool** Penn LDI Health Economist, May 2012; [Brown JC](#), [Winters-Stone K](#), [Lee A et al](#). **Cancer, physical activity, and exercise** *Compr Physiol* 2012; 2(4): 2775-809; [Rock CL](#), [Doyle C](#), [Demark-Wahnefried W et al](#). **Nutrition and physical activity guidelines for cancer survivors** *CA Cancer J Clin* 2012; 62(4): 242–74; [Macmillan Cancer Support](#) - **The importance of physical activity for people living with and beyond cancer** 2012; [Carayol M](#), [Bernard P](#), [Boiché J et al](#). **Psychological effect of exercise in women with BREAST CANCER receiving adjuvant therapy: What is the optimal dose needed?** *Ann Oncol* 2012; 24(2): 291-300; [Yeo TP](#), [Burrell SA](#), [Sauter PK et al](#). **A progressive postresection walking program significantly improves fatigue and health-related quality of life in PANCREAS and periampullary cancer patients** *J Am Coll Surg* 2012; 214(4): 463-75.; [Adamsen L](#), [Stage M](#), [Laursen J et al](#). **Exercise and relaxation intervention for patients with advanced LUNG CANCER: a qualitative feasibility study** *Scand J Med Sci Sports* 2012; 22(6): 804-15.

3 [Brown JC](#), [Winters-Stone K](#), [Lee A et al](#). Cancer, physical activity, and exercise *Compr Physiol* 2012; 2(4): 2775-809.

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[Mustian KM](#), [Alfano CM](#), [Heckler C et al](#). Comparison of pharmaceutical, psychological, and exercise treatments for cancer-related fatigue: a meta-analysis *JAMA Oncol* 2017; doi: 10.1001/jamaoncol.2016.6914.

5. Communication and awareness raising

5.1 Press relations: press breakfast with Board Members

Duration 4 months

Context

Brussels, heart of European lobbying, gathers many cancer organisations craving attention from decision-makers and the media. Even though they do not pursue exactly the same goals, the EU bubble is so busy that there is fierce competition between them.

Objectives

- To raise ECPC's profile and be unanimously viewed as THE cancer patient organisation
- To stress the difference with other cancer organisations
- To become the reference organisation on any cancer related issue for journalists

Actions

- Organisation of two one and half hour press breakfast events
- Definition of an agenda that both meets ECPC's priorities, the EU agenda and citizens' concerns
- Preparation of key messages and wording
- Identification and invitation of journalists
- Briefing the Board Members who will attend (maximum 4) and the Director
- Follow up with the journalists
- Promotion of the press coverage

Timeframe / milestones

Month 3-5 1st event

Month 10-12 2nd event

Deliverables

- 2 press breakfast event reports

5.2 Support to Policy work and Health & Research projects

Duration: 12 months

Context

An effective communication can have boosting effect on successful project execution, that's why the communication team needs to be involved in all ECPC projects from the beginning to be able to advice and set up a communication strategy. Only successfully promoted projects will have an impact on our members.

Objectives

- To make sure ECPC projects receive the attention they deserve
- To increase ordinary people outreach of research, EU Affairs, EU projects, campaigns, awareness days in general
- To strengthen ECPC image of being a trust-worthy partner for projects and funding
- To become the reference in cancer patient field

Actions

Actions may vary from project to project.

- Project team briefs ECPC Communication team about the future project.
- Set up regular TCs to brief the communication team on the implementation status of the project.
- Creation of a communication strategy and calendar for each project
- Drafting, editing, laying out and dissemination of project deliverables through posts, mailings, websites, brochures, posters, press releases

Timeframe / milestones

Depends on a project and its timeframe.

Beginning of the project: Communication team is briefed about the project and approval of the communication plan

Throughout the whole project: Implementation of the communication plan

End of the project: Press release and impact report

Deliverables

- Communication and Dissemination Plan
- Social Media Posts
- Content for website
- Press Releases
- Mailings, newsletters
- Poster, brochure, leaflet

5.3 Podcasts of interviews

Duration 12 months

Context

One of ECPC's challenges is to translate EU jargon and scientific topics – both at the heart of its activities - into clear and appealing content for its various audiences.

Objectives

By its nature and its missions, ECPC wants to be an organisation with a human face to give its Members an image they identify with and to position ECPC as a cancer patient organisation and not another cancer organisation.

Actions

Creation and promotion of topical podcasts interviewing ECPC team, Board Members, partners and experts to inform ECPC's audiences about our work and crucial matters discussed in Brussels and in the scientific community.

Timeframe / milestones

Month 1-2 Creating an editorial policy, guidelines and agenda

Month 2 Contacting interviewees

Month 3 Interviewing them

Month 3 Editing the audio files

Month 3 Disseminating and promoting the podcasts

Deliverables

- Editorial policy and guidelines
- Podcast report

5.4 Social media strategy

Duration: all year long

Context

Reach and visibility are crucial aspects of any prosperous project or organisation. To be impactful online, ECPC needs to target the right audience and constantly improve the engagement with them. Sharing comprehensible, relevant and appealing (design, layout, format) content increases the willingness of ECPC target audience to actively participate on our social media accounts which bring us further visibility and expand our reach. The broader we spread information related to cancer, the greater attention we receive.

Objectives

- To increase the reach and visibility of any topic / campaign we tackle
- To gain active followers who are ready to back our initiatives and disseminate our messages
- To become a relevant and trusted source of information on social media
- To become a legitimate and direct intermediate between patients and decision makers at EU level
- To become a demanded partner for project cooperation / funding / campaigning
- To become an inspiration for our members

Actions

- Analyses of our target audiences: the audience we own, the audience we want (journalists, decision-makers, potential partners, potential funders), and drive their audience towards us
- Draft guidelines for different audiences (laics and professionals)
- Year plan of our Social Media content
- Start a new way of communication (podcast)
- Regularly analyze our performance to improve

Timeframe / milestones

Month 1 Searching for the best solution for analyses

Month 1 Preparation of the Social Media calendar 2020, scheduling posts

Month 1 Drafting guidelines, briefing the staff about guidelines

Month 2-4 Implementation of new communication tools and communication methods

Month 5 Evaluation, adaptation if needed

Month 6 Special focus the annual congress and AGM (live video, more structured and in-depth live tweet, interviews, survey, etc.)

Month 12 Preparation of the Social Media calendar 2021

Deliverables

- Audience analyses report
- Communication guidelines
- Social Media Calendar

5.5 Interactive map of ECPC Members

Duration: 12 months

Context

The new website is the only professional communication tool to present ECPC work and its members. ECPC is the voice of European Cancer Patients and the interactive map can help to showcase not only location of our members, but the tool gives them an opportunity to send to the world a message through us, as it will include pictures and quotes with key messages relevant to each member and country. Working on such specific project where members are actively involved in the production process can help to increase their sense of affiliation and foster future cooperation.

Objectives

- To increase visibility of ECPC and ECPC Members
- To create an interactive tool to showcase the variety of challenges cancer patients face in their specific context

Actions

- Identification of members and selection of a country representative who will be showcased in the map
- Collection of quotes and pictures following GDPR rules
- Pictures of members taken by a professional photographer, if needed
- Development of the tool based on our requests by an agency or graphic designer
- Promotion of the tool

Timeframe / milestones

Month 1 Start of the project, briefing an agency, contacting members (2 months)

Month 3 Selecting representatives, collecting pictures and quotes from members (3 months)

Month 6 Engaging a professional photographer who can take profile pictures of the selected members attending ECPC annual congress (only if it's needed)

Month 10 Delivery of the interactive tool

Month 11 Launch of the interactive map

Deliverables

- Database of photographs and quotes
- Interactive map
- Dissemination plan

5.6 Communication tools

Duration 12 months

Context

ECPC's mission is to represent more than 450 Members from 49 countries. The challenge not only consists of the scale of the coalition but the diversity of its members. They include numerous cancer types, various organisation sizes and resources, national and regional specificities. With limited possibilities to visit each of them, digital tools are key to know them, bound with them and answer their needs.

Objectives

To create a sense of community we need:

- To inform Members with updates on the Secretariat and Board work and crucial matters discussed in Brussels
- To spark off their interest and engagement to provide us with:
- Information about their own challenges and needs
- Their own content, successes and opportunities to share

Actions

- Implementation and dissemination of a quarterly newsletter with regular, relevant, useful and exciting news from Brussels and from members
- Consolidated version of the website with a glossary of technical terms, a library of cancer patients testimonials, inventory of press coverage of ECPC's activities to facilitate listening and answering members' needs
- Develop a social media strategy to promoting members and ECPC work

Timeframe / milestones & deliverables

Month 4 Launch of the quarterly Newsletter

- Identifying members for interviews on their needs: January
- Drafting content: February
- Testing the content on these members: March
- Laying out: April
- launching the Newsletter: April

Month 4-6 Consolidated version of the website

- Glossary of technical terms, press coverage: April
- Library of cancer patients' testimonials: May – June

Month 1-12 Social media strategy:

- Promoting members work and ours: all year long
- Consulting members to know their needs and goals with regular quarterly short surveys

5.7 Annual report

Duration 6 months

Context

ECPC operates in a fairly complex environment: at the crossroad of cancer patient member organisations from 49 countries, the EU bubble (including decision-makers, partners and the media), the research community and pharmaceutical companies. Its annual report delivers an exhaustive and clear presentation of the organisation annual achievements in one single document, readable by anyone.

Objectives

More than an administrative obligation, the annual report fulfils several goals:

- Transparency: accurately informing members of ECPC's work over the past year
- Fund raising: detailing how the money was spent the year before, the annual report demonstrates the efficiency of ECPC's past Action Plan to current and possible future funders
- Partnerships: opportunities for new partnerships can be created based on current projects targeting specific matters for cancer patients and on the capacity of the organisation.

Actions

- Gathering information on projects as well as data, testimonials and illustrations
- Writing in a concise way and highlighting key information
- Laying out in a user-friendly manner
- Printing 500 copies
- Dissemination (hard copies sent to selected partners) and promotion of the report on social media

Timeframe / milestones

Month 1-2 Gathering information

Month 3 Writing the report

Month 4 Laying out

Month 5 Printing

Month 5-12 Disseminating and promoting

Deliverables

500 copies of the annual report (+/- 64 pages)

6. Strategic Alliances

European Medicines Agency

The European Medicines Agency (EMA) is an agency of the EU responsible for clinical efficacy assessment of medicines, ensuring that all medicines available on the European market are safe, effective and of high quality.



ECPC expresses the views of people with cancer as an accredited member of the Patients' and Consumers' Working Party (PCWP), the main patients' working group within the EMA and the Committee for Medicinal Products for Human Use. The role of the Patients and Consumers' Working Party is to advise, initiate discussion and propose solutions to all important matters related to medicines' authorisation and safety, but also to educate patients about the medicines which they use.

ECPC is represented in the Technical Anonymization Group (TAG), created by EMA on the regulatory needs connected to medical, clinical and research data transparency. Additionally, ECPC involves patient representatives in Scientific Advisory Groups and other scientific advice procedures of the European Medicines Agency. These patient representatives share their real-life perspective and experience in relation to medicines in their disease area.

ECPC also participates in the Steering Committee of the ENCePP-European Network of Centres for Pharmacoepidemiology and Pharmacovigilance at the European Medicines Agency, where she represents the Patients and Consumers Working Party. ECPC contributed as co-author in the recently published „The ENCePP Code of Conduct“, presenting the patient perspective on the scientific independence and transparency in non-interventional post-authorisation studies and attended the virtual and in person meetings of the ENCePP.

ESMO

In 2020, ECPC and the European Society for Medical Oncology (ESMO) will continue the long-established partnership and will implement the actions and commitments agreed in the Memorandum of Understanding. The existing cooperation will continue and efforts will be made to achieve their common goals and objectives in the field of cancer to satisfy new needs and new rights of people with cancer across Europe.



ESMO Guidelines

ECPC is directly involved in drafting updates of new ESMO Clinical Practice Guidelines. Updated regularly by the ESMO Guidelines Committee, the Guidelines are the standard for best practice of a vast variety of cancers, and represent the most reliable, evidence-based resource to help oncologists in taking practical decisions that affect patients' lives. ECPC and ESMO decided to partner to include more patient-friendly and solid information in the guidelines. To do so ECPC invites relevant Members to assess the information material to make sure, it is understandable for patients. In the last few years, each updated ESMO Guideline contained a reviewed, patient-oriented survivorship chapter. Simultaneously, ECPC published on its website all ESMO Guides for Patients, an invaluable source of information, which is often overlooked by those that could benefit the most.

Survivorship Guide

The ECPC-ESMO Survivorship Guide, a useful tool for patients and physicians offering a concise but comprehensive summary of the patient pathway from diagnosis and treatment to follow-up care, is available in English, German, Greek, Spanish, French, Croatian and Italian and is accessible on the ECPC and ESMO websites. In 2020, ECPC will continue its collaboration with ESMO on disseminating the guide through various channels, including workshops in different countries.

ESMO Congress

As every year, ECPC is present at the ESMO Annual Congress, the biggest European congress for the oncology community. The event is an opportunity for hundreds of patient advocates to network and offers the possibility to discuss vital issues and challenges faced by cancer patients.

ECPC, as a former Member of the ESMO Patient Advocates Working Group (PAWG), actively participates in the patient advocacy track that now is integrated in the scientific program. The main mission of the ESMO PAWG is the optimisation of patient care in Europe and worldwide, the continuous improvement of cancer-specific information and education, the strengthening of patient autonomy and the support of patient rights.

ECCO Patient Advocate Committee

ECPC is a member of the European CanCER Organisation (ECCO) Patient Advisory Committee, which was established to contribute to the European Cancer Congress by



providing the patients' perspectives and by helping healthcare professionals and all delegates to better understand the "preferences" of patients, rather than just their perceived "needs".

All.Can

ECPC is one of the founding members of All.Can, an international multistakeholder initiative set up to optimise the efficiency of cancer care by focusing on improving outcomes for cancer patients. It was established to create political and public engagement around efficiency's improvement in cancer care. ECPC is a member of the Steering Committee and actively participates in its governance and working groups.



Union for International Cancer Control (UICC)

The Union for International Cancer Control (UICC) is dedicated to taking the lead in convening its annual congress, actively working on capacity building and advocacy initiatives that unite and support the cancer community to reduce the global cancer burden, promote greater equity, and to ensure that cancer control continues to be a priority in the world health and development agenda. UICC is governed by its member organisations which meet in a general assembly every two years, including the world's major cancer societies, ministries of health, research institutes and patient groups. ECPC is a Full Member of the Union and keeps close ties with the leadership to identify future areas of collaboration. In 2019 ECPC co-hosted an event with HRH Princess Dina Mired, President of UICC, in Bucharest.



Organisation for European Cancer Institutes (OECI)

ECPC and the Organisation of European Cancer Institute (OECI) continue their collaboration aiming at reducing fragmentation in cancer



care and at giving to all European cancer patients the possibility of receiving the best available care. . Since signing a Memorandum of Understanding in 2015, this powerful partnership aims to collect, analyse & disseminate successful, patient-oriented collaborative practices in cancer care and research.

European Organisation for Research and Treatment of Cancer (EORTC)

ECPC continues the ongoing partnership with the European Organisation for the Research and Treatment of Cancer (EORTC), one of the most important academic research institutions in the field of cancer in Europe. The EORTC aims to improve the standards of cancer treatment by testing more effective therapeutic strategies based on drugs, surgery and/or radiotherapy.



ECPC and EORTC have signed a Memorandum of Understanding in 2017 to formalise and strengthen their partnership. Collaborating activities include the organisation of seminars, meetings, roundtables, joint projects, training and joint publications.

ECPC closely collaborates with the EORTC/QoL group that conducts research to better understand the effects of cancer and its treatment on the health-related quality of life of diverse populations of patients with cancer, across different cultures.

European Association of Urology

The European Association of Urology (EAU) is the leading authority within Europe on urological practice, research and education. Its mission is to raise the standard level of urological care and to facilitate the continuous development and improvement of urology in Europe and beyond.



In 2018, ECPC and EAU have signed a Memorandum of Understanding (MoU) to formalise their partnership, which has been ongoing since 2015. It enables the collaboration between both organisations and facilitates the implementation of joint projects.

In March 2019 at the EAU congress in Barcelona, the EAU Patient Advocacy Group (EPAG) was launched and ECPC is a founding and active member.

European Alliance for Personalised Medicine

ECPC is one of the founding members of the European Alliance for Personalised Medicine (EAPM), which brings together professionals and patient advocacy groups, with extensive scientific, clinical, caring and training expertise in Personalised Medicine and diagnostics, as well as leading academic institutions, industry and other expert stakeholders.



European Alliance for
Personalised Medicine

Cancer Drug Development Forum

The Cancer Drug Development Forum (CDDF) aims to provide a unique platform to facilitate interactions between all stakeholders (academia, regulatory authorities, policymakers, the pharmaceutical industry and patient advocates) and to ultimately increase efficiency in the development of cancer drugs.



CDDF
Cancer Drug Development Forum

ECPC sits in the Board of CDDF and actively contributes to committees of various events organised by CDDF.

European Society of Surgical Oncology

The European Society of Surgical Oncology (ESSO) aims to advance the science and practice of surgical oncology for the benefit of cancer patients. The organisation has established a Patient Advisory Group (PAG) within its structure to incorporate the perspective of patients.



esso
THE EUROPEAN SOCIETY
OF SURGICAL ONCOLOGY

ECPC is member of the PAG and has contributed to its work supporting the

pursuit of surgical specialisation in oncology. ESSO leads a range of activities related to education, research and leadership in multidisciplinary care.

According to its vision, ESSO represents the most established cancer treatments and develops standards for the care of cancer patients through its core values as well as its activities in the field of education, homogenisation of skills, quality healthcare and, ultimately, qualification.

Biobanking and Biomolecular Resources Research Infrastructure

The Biobanking and Biomolecular Resources Research Infrastructure - European Research Infrastructure Consortium establishes, operates and develops a pan-European distributed research infrastructure of biobanks and biomolecular resources, aiming at facilitating the access to resources as well as facilities, and to support high quality biomolecular and medical research.



In 2018, ECPC joined the BBMRI-ERIC Stakeholder forum, which is the main interface for European patients' organisations, civil society, industry and academia to interact with the biobanking universe. The role of stakeholders is enshrined in the BBMRI-ERIC statutes: as one of the advisory boards, the Stakeholder Forum contributes to the decision-making process of BBMRI-ERIC, together with the Scientific and Ethical Advisory Board (SEAB). ECPC representation ensures we are on the forefront of biobanking developments necessary for biomedical research.

WIN

The Worldwide Innovative Networking (WIN) Consortium in personalised cancer medicine's includes members that are leading organisations, representing all stakeholders in the personalised cancer medicine field. The shared vision of the Worldwide Innovative Networking Consortium aims to deliver effective and personalised cancer medicine to patients worldwide. Two ECPC representatives sit in the General Assembly of the WIN Consortium.



The WIN Symposia, held annually in Paris, gathers a breadth of stakeholders from all around the world to learn, share and collaborate.

European Federation of Pharmaceutical Industries and Associations

ECPC actively participates in the EFPIA Patient Think Tank, a forum for an open exchange of ideas and information between Patient Organisations and industry on issues impacting on patients. ECPC is a member of the EFPIA Oncology Platform – bringing together European cancer patient organisations and the industry to find approaches and solutions to common challenges faced by cancer patients across Europe.



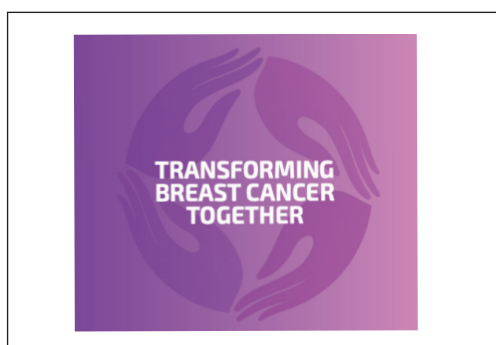
EU4Health

ECPC is a member of the civil society campaign EU4Health, which brings together over 241 organisations that share the vision of a Europe where all people are as healthy as they can be throughout their lives. The campaign aims to ensure that EU action on health remains strong after 2020 through active engagement with EU and international policymaking bodies on health policy. The campaign is led by the European Patients Forum and the European Public Health Alliance.



Transforming Breast Cancer Together

The Transforming Breast Cancer Together initiative was established in November 2017 and brought together a number of policy makers and organisations deeply committed to cancer care. The ultimate goal of this



initiative is to improve services for patients in an area of still high unmet needs and reduce the societal impact of breast cancer by elevating it as a health policy priority in order to improve breast cancer prevention, diagnosis and care across Europe.

Throughout 2018 and 2019, ECPC together with the members of the group executed several awareness raising activities under the concept of a “String of Pearls”, where each activity aimed at raising awareness of pressing issues concerning breast cancer represents a new ‘pearl’ on the string.

EU Health Coalition

The EU Health Coalition is a multi-stakeholder initiative looking at how we map the future of healthcare in Europe, making the most of the innovation at our fingertips, and what is the role of the European Union in addressing these challenges. ECPC and members of the coalition co-

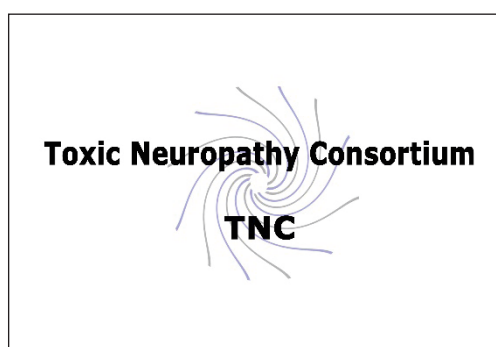
created a set of principles that outline our vision for health in Europe at the first ever EU Health Summit in 2018 and continue to work together beyond the event to introduce our vision to other key stakeholders and the incoming European Commission and European Parliament.



Toxic Neuropathy Consortium

ECPC and the Toxic Neuropathy Consortium (TNC) signed a Memorandum of Understanding in May 2019 to strengthen the mutual collaboration. TNC aims at increasing the engagement of all the relevant stakeholders to improve

knowledge and find solutions to the medical and social problems related to toxic neuropathies. TNC as a Special Interest Group was created at the 2018 Peripheral Nerve Society (PNS) meeting in Baltimore. The PNS is an international organization of physicians and scientists working together to develop and provide the best treatments for people who have peripheral nerve diseases.



NCD Alliance

ECPC joined the Non Communicable Disease (NCD) Alliance in 2018. This is a recognised global thought leader on non communicable disease policy

and practice, a convener of the civil society movement, a partner to governments and UN agencies, and an advocate for people at risk of or living with NCDs. It has a robust global network of more than 2,000 organisations in 170 countries. This includes global and national NGOs, scientific and professional associations, academic and research institutions, private sector entities and dedicated individuals.



European Society for Blood and Marrow Transplantation

The European Society for Blood and Marrow Transplantation (EBMT) is a collaborative peer network of professionals working, in centres and as individuals, in the field of clinical bone marrow transplantation and cellular therapy. Together, they make up the membership of our organization. Members contribute to and benefit from the collective knowledge that the EBMT has accrued, with the ultimate goal of saving the lives of patients with blood cancers and other life-threatening diseases.



In 2018, ECPC and EMBT signed a Memorandum of Understanding to enable coordination and cooperation in carrying out activities of common interest. This will include organisation of events, collaboration on joint projects and publishing jointly.



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