



European Cancer  
Patient Coalition

# Action Plan 2022

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**European Cancer  
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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 470 members in 50 countries representing all EU Member States and Norway, Ukraine, Belarus, Switzerland, Bosnia and Herzegovina, Serbia, USA, Canada, Brazil, 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 2021 achievements

In year 2021 the challenges of year 2020 continued for both the cancer community worldwide and ECPC. The COVID19 pandemic continued to spread around the planet, sending billions of people into lockdown as health services struggle to cope. As this disease can endanger cancer patients directly or indirectly, ECPC has been strongly committed to provide its members and the larger cancer community with the most updated information also on the vaccines to ensure that cancer patients are safe and protected during the pandemic.

The coronavirus pandemic has severely disrupted cancer care, revealed weaknesses of health systems, and it will have a significant impact on new cancer diagnosis in the following years. This situation has led ECPC to prove its resilience, adaptability and commitment to its mission: a Europe of equality, where all European cancer patients have timely and affordable access to the best treatment and care available, throughout their life.

For that reason, ECPC has continued working to ensure that the rights of cancer patients are respected.

Kathi Apostolidis, the President of ECPC has been more than ever committed to promote patients' equality in cancer treatment and foster better quality of life for cancer patients and cancer survivors, in all of Europe.

She worked more closely with ECPC Members and stakeholders, as a multi-stakeholder approach is key to increasing the quality of life of cancer patients in Europe and beyond.

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

Work on other European Union funded projects continued, including 8 Horizon 2020 projects (DIAdIC, H2020MM04 DENIM, ImmunoSABR, LEGACy, PalliativeSedation,

LifeChamps, QUALITOP, Instand-NGS4P), 3 Innovative Medicine Initiative (IMI) projects (BD4BO PIONEER, Immune-Image, PREFER), Over 50 new project proposals were submitted, and 5 new projects were approved by the European Commission with ECPC as a relevant partner representing the patient voice (INTERVENE, TIGER, T2EVOLVE, OPTIMA, RAPTOR). The “Right to be Forgotten”, building on the success of the relevant laws in France, Belgium and Luxemburg fostered the implementation of the law in The Netherlands and Portugal.

Furthermore, exactly one year after the launch of the consultation period for Europe’s Beating Cancer Plan on World Cancer Day, the plan was launched. The “Challenge Cancer” Parliamentary Intergroup on Cancer strengthened its presence and action, and several events were organised and endorsed with the support of ECPC which is managing the secretariat of the Intergroup.

Innovative approaches to cancer treatment, diagnostic methods, introduction of big data and artificial intelligence to the diagnosis, treatment and prognosis of cancer, are at the centre of most new project proposals. ECPC follows closely the development in these fields and remains protagonist as expressing the patient voice on them e.g., personalised medicine, immunotherapy, biologic and biosimilar medicines, as well as new cancer diagnostics, including new biomarker tests, NGS-New Generation Sequencing and WGS – Whole Genome Sequencing. ECPC has started a new project in 2021 one on establishing a taskforce on Personalised Medicine to support its implementation throughout the Europe’s Beating Cancer Plan.

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

As research comes under the competence of the European Commission, but healthcare is a national competence, bio-medical research could serve as a catalyst between research and healthcare, thus, strengthening the social impact of translational research in cancer, integrating the patients’ perspective. ECPC acts as the missing link between all the relevant stakeholders, always keeping in mind patient centricity, ethics and sustainability. ECPC, based on its unique expertise and perspective, is the bridge between research and healthcare and works effectively with both. With this purpose in mind, ECPC will continue to engage with the oncology community and European Institutions on the principle of “Science with and for Society”.

ECPC collaborated closely with its Members across Europe on several awareness raising campaigns, including head and neck cancer, Merkel Cell Carcinoma, non-melanoma skin cancers and personalised medicine. ECPC’s fundamental role is to be the voice of its members in Europe and to represent them within European institutions. Each one of ECPC Member is essential for the work of the organisation.

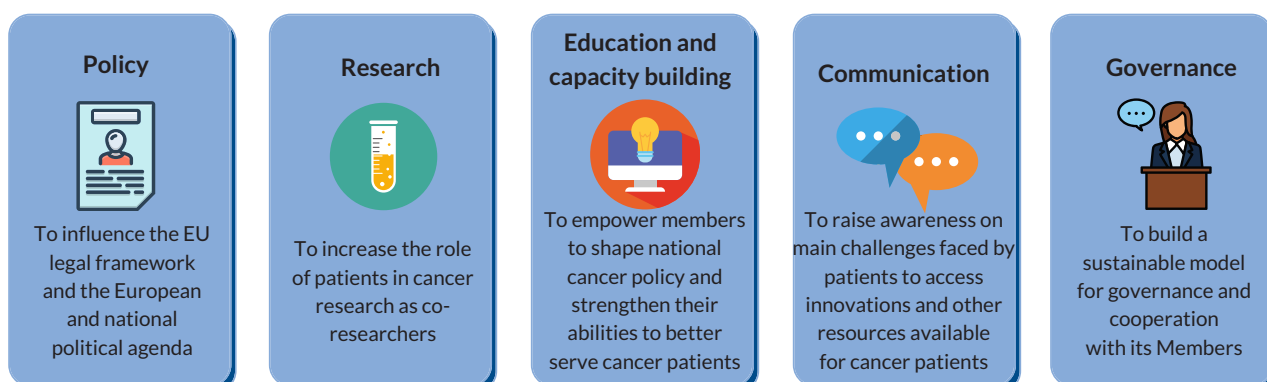
ECPC’s contribution to cancer research and care has been further recognised by having ECPC representatives invited to Boards and Committees of top-level European cancer organisations, such as Pancreatic Cancer Europe-PCE, WIN Consortium, BBMRI-ERIC, European Cancer Organisation – E.C.O., All.Can, EU Health Coalition.

## The European Cancer Patient Coalition Strategy

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

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

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



# 1. The European Cancer Patient Coalition Objectives

The main objectives of the 2022 Action Plan are to further support and advocate for cancer patient rights, to develop a strong engagement with the European Institutions members, to strengthen the connection with ECPC members, partners and stakeholders during a period of many challenges in both the internal and external environment.

## 1.1 Policy and Advocacy

ECPC's added value and main mission remain to be the voice of people with cancer in Europe. To do so, ECPC will continue to follow and contribute to a variety of policy issues at the European level, based on our Action Plan and Strategy and to follow and intervene in, where appropriate, the main EU health, research, and other relevant policy topics. In 2022, the European Cancer Patient Coalition will focus on developing the following main policy themes:

- Health technology assessment
- Personalised medicine
- Right to be Forgotten
- CAR T Treatments
- Cancer Complications & Comorbidities
- Challenge Cancer Intergroup
- Covid 19 and Cancer
- Non Melanoma Skin Cancer
- Big data and digital health
- Cancer and Inequalities
- Palliative and Complementary Care
- Cancer Mission
- Europe's Beating Cancer Plan

## 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's 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 2022 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 2022, ECPC will continue to contribute to on-going European research projects, as well as to join consortia to bid on new project proposals. ECPC is currently involved in the Innovative Partnership for Action Against Cancer (iPAAC), the ECIBC-European Commission Initiative for Breast Cancer, 9 Horizon 2020 projects (DIAdIC, EUCANCan, HTx, ImmunoSABR, LEGACy, PalliativeSedation, LifeChamps, QUALITOP, Instand-NGS4P), 3 Innovative Medicine Initiative (IMI) projects (BD4BO PIONEER, Immune-Image, PREFER) and 2 Innovative Training Networks (ITN) (ELBA and PREDICT). In 2020, the European Cancer Patient Coalition began work on its first project funded by the European Institute of Innovation and Technology (EIT) Health, "Empowering European Patients in Radiation Oncology" (E-PRO). In 2021 ECPC has kicked off 4 additional projects (T2EVOLVE, INTERVENE, OPTIMA and TIGER) and in 2022 RAPTOR will be kicked off. In addition, 11 European funded projects (UNCAN.eu, AIDAVA, canSERV, CGI-Clinics, EOSC4Cancer, INSPIRE, MyPath, PAINLESS, PAL-CYCLES, PREFERABLE-II, RELEVUM) will be kicked off in 2022.

## 1.3 Education & Capacity Building

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

ECPC is as strong as the bond between the organisation and its Membership. During the last years ECPC membership almost doubled. ECPC renewed its contacts with old and new members, despite, due to COVID-19 restrictions, in 2020 and 2021 we could not meet them at our Annual General Meeting that was held virtually in November. To maintain a strong trust with our members, we provide quality services to better respond to the needs of cancer patients' organisations on the field. For this reason, ECPC will invest time and resources to increase and potentiate educational and capacity building initiatives towards its members and empower them to advocate at country level also through sharing best practices.

The 2022 education and capacity building objectives are to increase and continue the dialogue between the Coalition and its Members to ensure increased capacity for both.

## 1.4 Communication and Awareness Raising

In 2022, ECPC will consolidate the work on communication and raising awareness campaigns.

The work on the website was consolidated in 2021 and in 2022 we will continue working on its update, daily maintenance and implementation with new features as we develop new projects.

Awareness campaigns on head and neck cancer, prostate cancer, personalised medicine, nutrition and physical activity, bladder cancer, non-melanoma skin cancer will continue in 2022, while new ones will be added. Throughout this year we have also supported several campaigns of our partners and members, and we will continue to do so throughout 2022.

## 1.5 Strategic Alliances

In the last decade, ECPC established and consolidated its relationship with several other non-governmental organisations and European Academic and Research Institutions, such as the Toxic Neuropathy Consortium (TNC), the European Society for Medical Oncology (ESMO), All.Can, Pancreatic Cancer Europe (PCE), the Cancer Drug Development Forum (CDDF), European Alliance for Personalised Medicine (EAPM), Worldwide innovative networking in personalised cancer medicine (WIN), The European Nutrition for Health Alliance, Federation of European Academies of Medicine (FEAM), Union for International Cancer Control (UICC), European Organisation for Research and Treatment of Cancer (EORTC), European Association of Urology (EAU), European Medicines Agency (EMA), European Cancer Organisation (ECO), the EU4Health CSO and the EU Health Coalition contributing to a compelling pack of joint initiatives.

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

## 1.6 How to read the Action Plan 2021

The Action Plan for the year 2022 gives the frames of ECPC activities. It was prepared for the AGM in November 2021. When the AGM made a decision not to approve the accounts of the year 2020, it was not possible to decide and put on effect the Action Plan 2022. ECPC is able to do new project and finance commitments for the year 2022 after the accounts for the years 2020 and 2021 are approved in the General Assembly of 28 May 2022.

The ECPC activities during the beginning of the year 2022 have been based on ongoing projects and their financing. The new board has the opportunity to adjust the Action Plan according to the available commitments and finance options.

ECPC action plan was revised to outline the main proposed activities for the second half of 2022. 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:** June 2022 – December 2022

#### **Context**

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

ECPC highlighted the severity of delays in the 2015 report **“Challenging the Europe of Disparities in Cancer”**, where access to life-saving cancer medicines was delayed for years mainly due to differences in Pricing & Reimbursement methodologies and HTA evaluations. The existing approach of parallel assessments by HTA bodies in every EU Member State, using different methodologies 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.

In January 2018, the EC set out a proposal for a regulation for future EU cooperation on HTA. The proposal focuses on the joint work on clinical aspects of HTA which are typically based on global evidence, while the non-clinical aspects remain at Member State level. This framework is the Joint Clinical Assessments (JCAs), which paired with non-clinical assessment (such as cost and economic evaluation, ethical analysis, organisational and legal aspects, patient and social aspects, including quality of life) would inform the real value of medicine for Pricing & Reimbursement (P&R) at Member State level. The European Parliament has already unanimously approved its negotiation position in February 2019 for inter-institutional negotiations with the Council and Member States, and strongly supports the EU JCAs. The ultimate goal is greater harmonisation of Pricing & Reimbursement and speeding up of JCAs, providing a pan-European indication of the real value of innovative medicines.

Before the end of 2021, the European Parliament is expected to vote in plenary to endorse the Health Technology Assessment Regulation that was agreed in June 2021 between the Parliament and Council.

In the 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, and advocate for it where there are no established frameworks for patient involvement in HTA. To further increase the impact of the HTA e-module, country-based workshops were organised in Poland, Greece, Portugal and Spain. Within 2020, ECPC developed a toolkit for patients and patient organizations on how cancer patients can be involved in the HTA process. The toolkit is country specific, as it has a sort of step-by-step guide for cancer patients to follow in order to be an active part of the HTA process in the respective country. As HTA processes vary within the EU countries, 2020 edition

focused on Spain and Portugal and provided information with regards to each Country's HTA system, the National and Regional HTA Agencies and what is the process for individual patients in order to be involved in a patient organization in their country.

The challenge though still remains with Member States. Up to now, what is established in the proposed EU regulation was not welcomed by all Member States, several of which have expressed strong reservations in the mandatory uptake of the JCA reports. ECPC will continue to monitor closely the progress in 2022.

## **Objectives**

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

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

ECPC aims at equipping its members by:

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

## **Actions**

- ECPC will translate and adapt the toolkit in at least 2 EU countries and languages and add country specific information.
- Raise awareness and build on the HTA workshops in 2 additional EU countries. ECPC will organise online workshops for patient organisations at a national level.
- ECPC will organize HTA trainings to activate member patient organisations, to prepare them with more detailed guidance on patient involvement in HTA in their countries and seek input from members in countries where patient involvement in HTA is more advanced.
- Training for HTA Experts

## **Deliverables**

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

## **Timeframe**

- Month 6-12 Update, adaptation and translation of the toolkit
- Month 6-12 Organisation of National Workshops
- Month 6-10 Organization of HTA trainings for activate member patient organisations

## **2.2 Personalised Medicine**

**Duration: January 2022 – December 2022**

### **Context**

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

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

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

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

One such way to address this is with molecular tumour testing, or biomarker testing, and personalised medicine, a targeted approach to the prevention, diagnosis and treatment of cancer. Awareness about molecular and genetic

tumour profiling remains low – only 23% of European doctors feel that their patients are always fully informed about molecular or biomarker testing. Through involvement in the Innovative Partnership on Action Against Cancer (iPAAC), ECPC will also use the contribution of the Joint Action on genomics to further increase awareness. The use of cancer molecular testing in Europe also varies by country, because in many countries diagnostic tests are not integrated into clinical practice and are not reimbursed or available to all people with cancer. This needs to change as it further creates inequalities in Europe.

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

## Objectives

ECPC aims to continue its efforts (See ECPC last campaign here: <http://www.ecpc.org/edu/personalisedmedicine>) to put personalised medicine for cancer prevention, diagnosis, prognosis and therapy into the spotlight of the European and national agenda.

In 2018, ECPC held an event in Brussels in collaboration with the Cancer Drug Development Forum (CDDF) and has launched the first-ever Personalised Medicine Awareness Month in November called “cracking the cancer code” with the aim to promote the importance of access to cancer biomarker testing and molecular testing. ECPC continued the pan-European campaign in 2019 and 2020 and also the collaboration with the European Alliance for Personalised Medicine (EAPM). In 2020 ECPC collaborated with the International Quality Network for Pathology (IQN-Path) to implement a survey among cancer patients to understand the gaps in knowledge and accessibility to biomarker testing across Europe. The results of the survey were launched in 2020.

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

However, as the use of cancer molecular testing in Europe also varies by country, ECPC will continue to advocate for a common European policy applied to all Member States that will integrate personalised medicine in oncology (genetic profiling, molecular testing) into clinical practice, secure fair reimbursement policies and accessibility to all European citizens who need it.

## Actions

In 2022 ECPC will work on the following actions:

- Raising awareness, towards creating a common European consensus and delivering more in-depth yet easy-to-understand patient information
- Using the experience and the outcomes of the joint action (partner in the Innovative Partnership for Action Against Cancer-iPAAC) to support a paradigm shift on the use of genomics
- Use the knowledge produced by several EU funded projects of which ECPC is a partner to support and promote the importance of Personalised Medicine

- Engaging with experts and policymakers to drive concrete policy recommendations stemming from policy discussion in the European Parliament
- Supporting a resolution to the European Parliament calling on the constant efforts and establishment of a wider coherence and the development of a Directive for personalised treatment for cancer prevention, diagnosis, prognosis and therapy and adaptation of the Directive from all Member States.

#### **Deliverables:**

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

#### **Timeframe:**

- Month 6-11: Planning and organisation of the personalised Medicine awareness campaign
- Month 6-10: Translation of the booklet into several EU languages
- Month 10-11: Dissemination of the booklet

## **2.2.1 Task Force on Personalised Medicine**

### **Background**

Europe's Beating Cancer Plan represents a turning point in European cancer policy. The Plan was based on extensive stakeholder consultation and is very comprehensive as a result. It sets out lofty ambitions to improve access to the latest innovations in cancer prevention, early detection, diagnosis, and treatment while also seeking to improve quality of life of patients and survivors.

The Plan also sets out how the EU will support Member States and where the €4 billion earmarked for actions addressing cancer will be drawn from. Personalised medicine is at the heart of the Beating Cancer Plan. The Plan clearly recognises the value of personalised medicine, a theme which cuts across many of the new initiatives it proposes to introduce, such as:

- Cancer Diagnostics and Treatment for All which will be launched in 2022 and aims to support greater sharing of tumour profile data with the aim of



optimising cancer diagnosis and treatment and reducing inequalities in access to personalised medicine.

- Partnership on Personalised Medicine which will be established in 2023 under Horizon Europe and will set out priorities for research and education, support research projects and make recommendations for the greater integration of personalised medicine in clinical practice.
- New collaborative projects in high performance computing and artificial intelligence to support treatment decisions and advance personalised medicine.
- A Cancer Inequalities Registry which will identify disparities and inequalities in cancer care between Member States and regions. This could include exploring inequalities in access to personalised medicine.

Despite these encouraging goals and promising initiatives, it is not clear how the proposed plans will materialise in practice. There is little information in the public domain about how the proposed initiatives are being developed and whether implementation will reflect lessons learnt from existing work across the region. There are several known policy and service delivery barriers preventing greater access to personalised medicine for cancer in Europe.

Variations in areas such as workforce capacity and quality, reimbursement, data infrastructure and awareness of patients, the public and policymakers are all important factors which have previously contributed to unequal access to personalised medicine.

Building on previous work, there is the need for a long-term, system-wide vision of personalised medicine across Europe. There are currently multiple efforts underway to raise awareness of the need to improve access to personalised medicine, however each tends to take a different lens.

A comprehensive approach looking at the links between diagnosis and treatment and broadening the definition of treatment to encompass nonmedicinal approaches such as surgery and radiotherapy, is needed.

This broad view of personalised medicine also needs to be brought into the Commission's initiatives on this topic, to make sure all cancer patients have access to personalised approaches in the broadest sense. With this goal in mind, the European Cancer Patients Coalition would like to establish a multi-disciplinary Personalised Medicine Taskforce which would aim to highlight key areas for consideration in the development of the Commission's proposed initiatives around personalised medicine.

This taskforce would draw from existing evidence and experience in trying to improve availability of personalised medicine across Europe and offer a platform to the European Commission where the implementation of personalised medicine within the frame of the Europe's Beating Cancer Plan can be discussed to better support the needs of cancer patients.

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

Previous ECPC work on the topic ECPC has been working on Personalised Medicine for several years and on different specific projects. In 2018 ECPC has launched the Personalised Medicine Awareness Month “Cracking the Cancer Code”, with a social media toolkit translated into several EU languages. In 2020 ECPC published “Personalised Medicine: A Guide for Patients” with Mark Lawler and participated in the IQN Path and EFPIA survey and report on Access to Quality Biomarker Testing in Europe. ECPC also published the White Paper “Investing in the Future - Improving cancer biomarker testing and cancer diagnosis for sustainable healthcare” together with the OncoHealth Institute and Fight Bladder Cancer UK, with the financial support of Bayer.

All this work will be the basis to build on the taskforce. Any duplication will be avoided. Previous work of sponsors and any other stakeholders involved in the taskforce will be considered in the development of the taskforce activities.

### **Aims, objectives, activities, and timeframes**

The overarching aim of this project is to ensure that the initiatives funded under Europe’s Beating Cancer Plan effectively support equal and timely access to personalised medicine across Europe, broadly defined to encompass all forms of treatment which take a targeted approach, including for example targeted radiotherapy, radioligand therapy and personalised medicines.

The activities have been planned to be as streamlined as possible so that policy recommendations are provided in a timely way, to inform the implementation of the Plan.

Activities would include:

- Drafting of an initial position statement on integrating personalised medicine into the implementation of the Beating Cancer Plan (September - October). This draft position statement will provide an initial basis for engagement with the EC and selected experts of the taskforce. It will be updated as the taskforce is established to reflect discussions and consultation both within the taskforce and with the EC.
- Establishing a multi-disciplinary taskforce on personalised medicine (September-December). The taskforce will be chaired by ECPC and will include approximately 10 leading stakeholders from across Europe.

Members would be asked to provide their time for free, and their involvement would be bound by co-signing the position paper. Members could include representatives from patient advocacy organisations, healthcare professional groups, the research community, and non-governmental organisations. We will draw on our existing networks to rapidly establish the taskforce, seeking to include organisations that are experienced in personalised medicine advocacy and policy shaping at a European level.

We would also seek to include experts involved in the delivery of best practice personalised oncology approaches in different countries. We would hold individual calls, as needed, with each confirmed member to understand their views on the draft position statement (see above) including key barriers and opportunities in personalised medicine for cancer, and how the work of the EC can best address

these through its proposed initiatives.

These calls will be instrumental in helping us to finalise the position paper and plan the agenda and content for an effective roundtable meeting (see below).

- Early and ongoing engagement with the European Commission (from September). We will approach the EC early in the project, to inform them about our work using the draft position statement as a basis.

We also hope to learn more about the status and intentions around the various Europe's Beating Cancer Plan initiatives and discuss possible opportunities for collaboration/input, and how we can best support them as they build their proposed initiatives.

- Planning and delivering a roundtable meeting of the taskforce (November). During this internal meeting we would hope to develop a consensus around the priority challenges preventing greater access to personalised medicine for cancer in Europe and identify key recommendations for the EC on how they could shape the Plan's initiatives to address these challenges.

The meeting will give due consideration to how the EC can best support Member States to address these challenges and recommendations identified. Discussions will be built into the evolving position statement.

- Finalisation of a public-facing position paper (September-November). This document will be based on the draft position statement noted above and will summarise the insights of the taskforce, drawing on discussions during the roundtable meeting and additional research as needed.

The report will include an outline of the key barriers/challenges which should be addressed and targeted recommendations for the EC. It will also include examples of good practice, presented as case studies which could offer learning to the EC and Member States.

- Virtual launch event (November). ECPC will co-host with the members of the taskforce an event to launch the report and seek support for its recommendations.

We would invite leading EC figures and taskforce members to attend and speak. We could also include a panel discussion and consider methods to allow for participant engagement e.g. breakout rooms and live e-polls on key discussion topics, as feasible within the time allowed. The launch could be held in November to coincide with the Personalised Medicine Awareness Month.

- Communications activities to disseminate our recommendations (November - December). We will leverage the recommendations through a communications campaign organised around the online event.
- Ongoing contact with the EC (December/January TBC). This would allow us to monitor and follow the progress of our recommendations and help determine any follow up activities or engagement opportunities that stem from this work.

Timelines above assume a rapid contracting process. Should this be delayed, timelines will need to be revisited. We may also wish to consider a longer-term

role for the group, perhaps meeting every quarter to discuss progress and provide ongoing input into the EC but this will depend on how the initial activities are implemented.

### **Project governance**

We propose the project is led by ECPC. ECPC will be broadly responsible for stakeholder engagement, including with the taskforce members and the EC. ECPC will also be responsible for project management, liaison with sponsors, research and drafting, and overall coordination of the taskforce meetings and engagement in drafting the position paper.

### **Role of sponsors**

We propose an arm's length role for sponsors so that the independence of the taskforce is maintained. In practice this will mean that although sponsors will not have a role in making decisions, they may provide suggestions for consideration. Specifically, we would invite sponsors to:

- provide suggestions for stakeholders to invite to join the taskforce
- be an equal partner to the taskforce with the opportunity to provide background materials, provide feedback on the draft and pre-final report. ECPC will collate and summarise this feedback like any other possible feedback from the other members of the taskforce.

## **2.2.2 White Paper on Personalised Medicine**

### **Background**

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

- Cancer Diagnostics and Treatment for All -to be launched in 2022
- Partnership on Personalised Medicine – to be established in 2023 under Horizon Europe
- New collaborative projects in high performance computing and artificial intelligence to support treatment decisions and advance personalised medicine
- A Cancer Inequalities Registry

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

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

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

### **Aims, objectives and activities**

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

The Member State to start with the pilot project is Germany.

Activities would include:

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

## **2.3 Right to be forgotten**

**Duration: January 2022 – December 2022**

### **Context**

The proportion of cancer survivors is increasing by 3% on a yearly basis and in 2020 around 14 million cancer survivors have been estimated in Europe.). Other studies based on projections estimated that given a population of 450 Mill in EU-27, the estimated number of cancer survivors should be 22.5 million.

Such numbers require increased attention to policies and best practices to ensure the highest level of quality of life and well-being of cancer survivors in Europe.

In this regard, returning to life in society after cancer can be challenging for several reasons. Survivors of cancer across Europe are experiencing several obstacles, in particular when looking for access to financial services, such as mortgages and insurances.

The activity promoted by the Right to be Forgotten Project is focused on legal research to assess the discriminatory practices and facilitate the promotion of equal access to financial services for cancer survivors in Europe. The objectives consist of facilitating the advocacy activity, providing a clearer legal background about the access to financial services for cancer survivors in the EU Member States, and developing the opportunity of the new regulatory framework at the EU level.

The main goal of the project is to contribute by offering an instrument to improve the quality of life and restore the well-being (including the economic one) affected by the illness condition of cancer survivors.

The strategy is focused on the awareness-raising and the empowerment of civil society, offering legal arguments to implement an EU legal framework, in order to support the project and the ECPC mission to affirm a right to be forgotten across Europe.

The project started in 2020 under the supervision of Dr Françoise Meunier and managed by Grazia Scocca (ECPC Legal Specialist).

On the basis of the previous actions provided, the next steps of the project include a campaign to support the implementation of the Beating Cancer Plan along with the recommendations of the European Cancer Mission and to ensure targeted activities in the field and an EU Legal framework.

Particularly important it will also be to continue with raising awareness actions in the EU Member States to support events and activity (e.g. survey) on the topic for cancer patients' national associations.

Moreover, the EU campaign to promote a Cancer survivors' day across Europe will be promoted further in cooperation with ECPC stakeholders. The initiative aims to have a European Cancer Survivors' Day as exists already in the USA and other Anglophone countries. This campaign would be beneficial for the Right to be Forgotten project, promoting the empowerment of cancer survivors in Europe.

To achieve in establishing an EU legislative framework on the matter is a long process that has specific procedures and timelines. In this regard, the process for the establishment of a Right to be forgotten should be likely accomplished by 2025. For the same reason in 2021, ECPC received an extension of funds for the project until 2025.

## **Objectives**

The "Right to be Forgotten" project aims to enable ECPC to build a strong evidence base to actively drive advocacy to enhance policy measures with European

institutions and Member States' governments to end discriminatory practices in financial services faced by cancer survivors in Europe.

The main goal of the project is to establish a legal framework on the Right to be forgotten in Europe.

### **Actions**

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

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

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

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

### **Deliverables**

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

### **Timeframe**

- Month 1-4 Data collection, analysis and update of the information on the impact and the level of implementation of the "Right to be Forgotten" laws, First EU parliament event
- Month 3-5 Right to be Forgotten Toolkit



- Month 6-9 (2nd) EU parliament event
- Month 6-12 Ad hoc meetings with relevant policy makers and stakeholders

## 2.4 CAR-T Treatments

**Duration: January 2022 – December 2022**

### Context

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

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

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

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

In addition, we conducted a literature review to support the development of 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. The topics tackled are:

- Accessibility
- Cross-border policies
- Pricing and Costs
- Health Technology Assessment (HTA) and Reimbursement



- Ethics
- Equitability
- Delivery
  - CAR-T delivery during COVID-19
  - Eligibility
- EU Regulations and Frameworks

The White Paper will be launched by the end of this year, on an online EU Parliament event co-hosted by the Challenge Cancer Parliamentary Intergroup to present the White Paper, to debate the benefits and risks of these new CAR T treatments, access barriers, treatment delivery, pricing and reimbursement as well other topics that may emerge, to present policy recommendations for the delivery of and access to these new treatments.

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

## **Objectives**

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

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

## **Actions**

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

- Further develop the platform of patients and caregivers, clinicians and other healthcare professionals, industry representatives, geneticists, pharma industry, payers and other experts and stakeholders to delineate the access problems from the patient perspective.
- Translate the White Paper into additional languages (n. of languages to be defined).
- Publish a toolkit for patients and caregivers explaining the details of the CAR-T treatment pathway and translate it in selected languages (n. of languages to be defined).
- Produce educational material of how patients can navigate online and have access to valuable information on CAR-T treatment and a glossary of terms to explain medical terms of the treatment in a patient friendly way. Both materials will be translated in selected languages (n. of languages to be defined).
- Organize a dedicated stakeholder conference co-hosted by the Challenge Cancer Parliamentary Intergroup to debate the benefits and risks of these new CAR T treatments, access barriers, treatment delivery, pricing and reimbursement as well other topics that may emerge, to present policy recommendations for the delivery of and access to these new treatments.

### **Deliverables**

- Stakeholders Platform
- Toolkit for patients and caregivers
- Translated version of the White paper
- Educational material
- Glossary of terms
- Translated version of the material and the glossary
- Dedicated 1-day stakeholder conference
- Activity Plan for the following year for ad hoc countries

### **Timeframe**

- Month 6–12 Further development of the CAR T Platform and constant increase of outreach and membership
- Month 6-8 Preparation of the toolkit
- Month 6- 10: Dedicated 1-day stakeholder conference
- Month 7-9 Preparation of the educational material and glossary
- Month 9-12 Translation of the materials produced and the White Paper in more languages

## 2.5 Cancer-related complications and comorbidities

**Duration: June 2022 – December 2022**

### Context

Cancer-related complications and comorbidities are a highly significant burden on patients across Europe. In many cases fatal, but they are too often neglected when it comes to policy and research. At present, there is a strong momentum in the EU policy landscape to bring attention to this area. The Europe's Beating Cancer Plan sets the agenda of the new Commission and of the Parliament. Cancer is set to become a top health priority for the next five years in the EU, with both the European Commission President, Ursula von der Leyen, and Commissioner for Health and Food Safety, Stella Kyriakides, having made clear that cancer will play a central role in their policy agenda and that the output will be the Europe's Beating Cancer Plan.

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

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

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

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

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

## **Objectives**

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

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

## **Structure**

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

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

- 1. European Cancer Patient Coalition (ECPC) - CHAIR**
2. Associations Collaborating on Hepatitis to Immunize and Eliminate the Viruses in Europe (ACHIEVE)
3. European Association for the Study of Obesity (EASO)
4. European Association for the Study of the Liver (EASL)
5. European Association of Urology (EAU)
6. European Brain Council (EBC)
7. European Cancer Organization (ECO)
8. Eurocarers
9. European Federation of Neurological Associations (EFNA)
10. European Federation of Nurses (EFN)
11. European Geriatric Medicine Society (EuGMS)
12. European Network for Smoking and Tobacco Prevention (ENSP)
13. European Nutrition for Health Alliance (ENHA)
14. European Pain Federation (EFIC)

15. European Society of Oncology Pharmacy (ESOP)
16. European Society of Surgical Oncology (ESSO)
17. European Society of Cardiology (ESC)
18. European Specialist Nurses Organisation (ESNO)
19. European Thrombosis and Haemostasis Alliance (ETHA)
20. Global Alliance of Mental Illness Advocacy Networks-Europe (GAMIAN-Europe)
21. International Psycho-Oncology Society (IPOS)
22. International Society on Thrombosis and Hemostasis (ISTH)
23. International Society of Geriatric Oncology (SIOG)
24. Thrombosis Ireland
25. Thrombosis UK
26. University KU Leuven (KU)
27. Leuven Cancer Institute (LKI)
28. Obesity Policy Engagement Network (OPEN-EU)
29. The European Federation of the Associations of Dietitians (EFAD)
30. The European Society for Clinical Nutrition and Metabolism (ESPEN)
31. The European Hematology Association (EHA)

ECPC is leading on the initiative and currently providing for the secretariat of the initiative. Dr Anna Falanga member of ETHA is the scientific lead of the initiative.

During 2021, the Joint Statement was updated two times to host the contribution of the newest members of the initiative. The number of the initiative members was increased by adding 7 organizations.

The White Paper on Cancer Comorbidities and Complications aiming to further communicate this issue at EU policy level and by individual organizations in their own activities, was also launched during 2021. In addition to this, a summary of the White Paper was produced.

During the European Week Against Cancer, and in the light of the EU Beating Cancer Plan, the ECPC, the Cancer Complications and Comorbidities Initiative Members and the European Parliamentary Intergroup “Challenge Cancer” co organised five webinars, taking place from Tuesday 25th to Monday 31st of May 2021. These webinars presented various issues surrounding Cancer Complications and Comorbidities, to ensure that Cancer complications and comorbidities are addressed in the implementation of the Europe’s Beating Cancer Plan and increase awareness on the relevance of these comorbidities among relevant stakeholders and the public.

Finally, ECPC with the contribution of the members of the Initiative, prepared and submitted to 22 MEPs who are also BECA committee members, 75 amendments on the BECA Committee draft report proposed by MEP Véronique Trillet-Lenoir on “Strengthening Europe in the fight against cancer - towards a comprehensive and coordinated strategy,” 43 of which were proposed by several MEPs to be included in the final version.

## **Actions**

- Joint Statement: A Joint Statement by all participating organisations serves to develop a joint call to action and the basis to unite all the members of the initiative. In broad terms, it calls for a move towards integrated care. This document can be used by the endorsing organisations in their own activities and in the discussion with EU policy makers. It has also been used for the open consultations on the Europe’s Beating Cancer Plan and the Cancer Mission. The document is yearly updated.
- Policy Paper: Based on the comprehensive literature review developed in 2020, a policy paper will be prepared and published in a peer-reviewed scientific journal.
- Online events: Building on the 2021 success, a series of events (live or online) on Cancer related complications and comorbidities will be organized. Several stakeholders from various sectors, cancer organizations, patients, caregivers and policy makers will be invited to participate.
- A European online survey to identify the needs, knowledge gaps and barriers of cancer patients suffering from cancer related complications and comorbidities will be developed
- Infographics and other visual materials per cancer-related complication and comorbidities to facilitate an impactful communication with patients, caregivers, policy makers and other relevant stakeholders. We will explore ways of making our message more engaging, such as by creating infographics.
- Event at the EU Parliament: An event at the EU Parliament will be organised to present the results of the European survey, sensitize MEPs on the issue and put forward the call to action within the context of the Europe’s Beating Cancer Plan implementation phase. It will be co-hosted by the Parliamentary Intergroup Challenge Cancer in Q3 of 2022.

## **Deliverables**

- Strategic plan for the year 2022
- Follow up meetings with relevant stakeholders
- Roadmap to monitor the implementation of Europe’s Beating CANCER Plan
- Results of the European survey
- A high-level meeting at the European Parliament
- Online events on Cancer comorbidities and complications

## Timeframe

- Month 6-12 Organization of follow up communications and meetings with relevant stakeholders, such as the European Commission for the Beating Cancer Plan, the Cancer Mission Board Chair, Challenge Cancer and MAC and other interested MEPs, such as the BECA group.
- Month 6-7: Convene a strategy planning meeting with the members of the initiative to identify the best strategy for the year and set up implementing actions
- Month 6-7: Prepare a Roadmap to monitor and influence the implementation of the Europe's Beating Cancer Plan
- Month 6-8: Publication of the Policy Paper on cancer
- Month 6-10: Launch of the European online survey on cancer-related complications and comorbidities
- Month 6-10: Organisation of the EWAC events
- Month 6-9: Infographics and other visual materials per cancer-related complication and comorbidities
- Month 9-12: Organisation of a high-level meeting at the European Parliament to present the results of the survey.

## 2.6 Challenge Cancer Intergroup

**Duration:** June 2022 – December 2022

### Context

- The new European Parliament Challenge Cancer Intergroup is the first and only EU Parliamentary Intergroup on cancer. It is chaired by MEP Cristian Buşoi, and co- chaired by MEPs Alessandra Moretti, Aldo
- Patriciello and Frédérique Ries, with the European Cancer Patient Coalition (ECPC) providing its Secretariat.
- The Intergroup was conceived by ECPC to ensure continuity in the European Parliament's work on cancer during the previous and the current mandates. The Intergroup serves as a forum for MEPs from all political parties to engage in dialogue with patients, cancer survivors, carers, scientific and medical societies, research institutions, think tanks, medical practitioners and researchers, policy makers and leaders of the health industry, civil society at large, national governments, and institutions. It acts as a two-way communication channel by holding hearings and debates and leading fact- finding missions on salient topics such as prevention, access to treatment, medicine shortages, cancer research on quality of life, innovation in cancer care, and survivorship.



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

## Objectives

- Based on the abovementioned, ECPC, with its 450 members of cancer patient organisations across the EU, aims to act as the intermediary between the Intergroup and European cancer stakeholders and civil society at large. The close collaboration of ECPC with the members of the Intergroup enables its members to access real testimonies and patient experiences, while allowing citizens to express their needs directly to European policymakers. This collaboration is aimed to provide a valuable contact point for MEPs with an interest in cancer policy to exchange views, best practices and access direct information on how cancer and its care are regulated in their countries.
- In its capacity as the Secretariat of the intergroup, ECPC wishes to work toward providing the members with access to real patient experience and a variety of European and national cancer stakeholders, while allowing citizens to express their needs directly to European policymakers. ECPC will make use of its ability, across its pan-European network of organisations, to share knowledge, to influence public health and cancer policies.
- Finally, thanks to the data gathered from various cancer sources, the Intergroup strives to influence the goals and guide the implementation of the Cancer Mission, Europe’s Beating Cancer Plan and other European cancer and health related policies.

## Actions

- In 2022 ECPC will work on the following actions:
- Ensuring the involvement of cancer research, prevention/health
- care and cancer patient communities at all stages of
- policymaking activities of the Intergroup
- Supporting EU measures and a resolution of the European Parliament, adapted for all Member States, on personalised treatment for cancer prevention, diagnosis, prognosis and therapy
- Discussing the cancer patients’ challenges in times of pandemics like COVID-19 and the role of policy makers in ensuring a more sustainable health system that will be able to cope with future crisis
- Raising awareness on the challenges that a cancer survivor faces during and after treatment and work with the members of the Intergroup to propose measures to improve the quality of life of cancer survivors during treatment and after (White Paper on Social Disparities, The Right to be Forgotten project)
- Advocating with the Cancer Mission Board and MEPs that are members of the



Intergroup on concerns related to cancer patients, survivors and carers

- Advocating on biosimilars and the policy measures needed to make such therapies available at the national level
- Supporting MEPs in the Intergroup to work with patient organisations at national level to ensure the timely and appropriate implementation of the EU Joint Action on Rare Cancers (JARC) recommendations for the Rare Cancer Agenda 2030 and that the Cross-Border Healthcare Directive is functional and its provisions accessible in the interest of rare cancer patients
- Advocating with MEPs to ensure that cancer-related complications and comorbidities are a central part of all policy discussions about cancer care and that they will be considered an individual pillar in the EU Cancer Plan
- Raising awareness on the importance of preventative measures, such as vaccines, and the importance that patient education plays in eliminating HPV-related cancers in Europe
- Discussing the cross-border challenges and potential policy solutions to ensure patients' access to CAR T cell therapies
- Informing MEPs on the effectiveness of involving patients and their representatives in the HTA process
- Raising awareness on the cancer patients' high risk of healthcare-associated infections and work with MEPs to ensure that this aspect will be addressed in the long-awaited legislative proposal by the European Commission on antimicrobial resistance (AMR)
- Informing MEPs about the importance of the complementary cancer treatments, such as physical activity and nutrition, and their role to propose measures to integrate such treatments in the clinical practice at the national level
- Discussing and proposing solutions on how the EU can use digital innovation to offer cost-effective tools to support the transition from a hospital-based healthcare model to a person-centred and integrated model, improve health promotion, prevention and access to care, and contribute to the sustainability and resilience of healthcare systems
- Raising awareness on rare cancers, such as Pancreatic Cancer and Merkel Cell Carcinoma and on a number of cancers, such as Bladder, Non Melanoma Skin Cancer and Breast Cancer, which have a high social and economic impact
- Engaging with MEPs and experts to drive concrete policy recommendations stemming from policy discussion within the Challenge Cancer Intergroup

**Deliverables:**

- Informative webinars for MEPs, their assistants and their policy advisors on cancer-related priorities
- European Parliament resolutions (no. to be identified)

- Internal meetings for the members of the Intergroup where MEPs can debate on the proposed topics and decide on the legislative steps to be taken
- Support Challenge Cancer Intergroup MEP members to incorporate the thematic of the Intergroup in external meetings and events

#### **Timeframe:**

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

## **2.7 Covid19**

**Duration:** June 2022 – December 2022

#### **Context**

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

The causes of COVID-19–related deaths are not clearly defined in the international reports available so far, but data from Italy, where +20% of all COVID-19 mortality was among cancer patients, amplify the importance of the #StayHome request of national health authorities. This confirms the WHO indication that older people are more vulnerable, particularly when they have underlying health conditions such as chronic lung disease, cardiovascular disease, diabetes, chronic kidney disease and active cancer.

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

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

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

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

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

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

## Objectives

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

- Continues updates and translations of the guidelines
- Development of factsheets
- Possible psychological support to cancer patients at the time of COVID-19 and during the vaccination period, depending on funding available
- Continues to support and monitor any irregularities in terms of treatment and vaccination for cancer patients during 2022
- Support Cancer Patients based on the need identified through the survey conducted during 2020

## Actions

- Update of the COVID-19 hub
- Publish, update and translate the COVID-19 statement and guidelines for cancer patients
- Survey on COVID-19 and cancer patients to better understand the consequences of covid 19 during 2022. ECPC will conduct a second wave of its survey on how

the Member States responded to the pandemic in relation to cancer patients. We aim also to investigate the impact of the pandemic to cancer patients caregivers around Europe and the impact of the vaccination, any obstacles, procedure or availability issues and side-effects will be investigated.

- The results will be available on the ECPC website and shared through social media (through clear messages such as infographics) and will serve as a basis for an open letter or press release.
- Publication of the survey results into a peer-reviewed indexed scientific journal
- Social media campaign spanning the COVID-19 epidemic and informing the general public and policy makers on the challenges cancer patients are going through
- COVID-19 Follow up with a publication on lessons learned and recommendations for policy makers
- Organisation of webinars to inform and empower cancer patients
- Collection of patient stories highlighting the challenges faced with COVID-19. These are to be shared on the ECPC website and further disseminated through social media together with interviews with healthcare professionals, epidemiologists and cancer patients.

### **Deliverables**

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

### **Timeframe**

- Month 6: Media strategy update of COVID-19 hub and COVID-19 statement
- Month 6-12: Guideline's translations- updates, Statement translations updates, patient stories, interviews
- Month 6-10: Webinars, recommendations, COVID-19 psycho-social support recommendations and factsheet, policy paper with recommendations as a

COVID-19 follow up, Patients stories and additional interviews

- Month 6-10: COVID-19 survey for cancer patients and caregivers
- Month 11-12: Submission of the survey results for publication

## 2.8 Non-melanoma skin cancer

**Duration:** June 2022 – December 2022

### Context

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

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

NMSC patients also inevitably endure a considerable reduction in quality-of-life due to the chronicity of this highly recalcitrant disease. NMSC patients often undergo repeated surgery, generally on visible areas such as neck or arms. Hence, they may suffer significant consequences for their appearance, self-esteem, and well-being. Furthermore, the quality of life of informal carers is also affected by the occurrence of NMSC. These carers are currently providing around 80% of care across the EU, and while doing that they may face physical, emotional, social, and financial distress. The carer role involves performing multiple roles and tasks which may lead to the neglect of their own needs. Consequently, informal carers have high psychological morbidity.

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

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

In addition, on 8<sup>th</sup> and 12<sup>th</sup> October, the follow-up workshops of the Multi-Stakeholder Summit on Occupational Skin Cancer (OSC) by solar UV radiation (UVR) at the workplace co-organized by ECPC and EADV brought together more than 30 participants from across the world, representing patient advocacy groups, workers unions, occupational safety and health professionals, social security representatives, dermatologists, and oncologists. The follow-up workshops of the Multi-Stakeholder Summit on OSC provided the optimal opportunity to build consensus around the key necessary steps to improve NMSC and OSC reporting, the needs of the NMSC community and the potential benefits of official recognizing NMSC as an occupational diseases. A representative of the European Commission's team working on Europe's Beating Cancer Plan (EBCP), and two Members of the European Parliament sitting on the Parliament's Special Committee on Beating Cancer (BECA) also took part.

This effort continued during 2021, with 2 online events. The first was entitled: Non-melanoma skin cancer as an occupational disease. What is the impact on the society and the welfare system and how can this be addressed from Europe's Beating Cancer Plan? It was held on the 15th June 2021 with representatives from the European Commission, the European Parliament, academia, work associations, cancer and patients organizations, patients and caregivers. The second was organized on the 28th October 2021 and it was entitled: NMSC in Europe: Tackling health inequalities, raising awareness of patients and informal carers, and improving their quality of life. The event was supported by EADV and EUROCARERS. In 2021, the NMSC hub was updated with material on prevention but also on the burden of caregiving to NMSC patients.

## **Objectives**

ECPC aims to:

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

## **Actions**

ECPC will build on the past year's developments to update and conduct the "Facing the Sun" social media campaign by producing a new toolkit with material such as videos, factsheets and other material to be added on the online hub. The toolkit will be available for ECPC member organizations to use at national level and translated on selected languages. The new toolkit will be launched during the Skin Cancer Awareness Month.

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

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

### **Deliverables**

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

### **Timeframe**

- Month 6-9: Production of the Toolkit for social media campaign material
- Month 6: "Facing the Sun" social media campaign implementation
- Month 6: ECPC - EADV joint workshop
- Month 7-11: Patients testimonies booklet
- Month 6-12: ad hoc meetings with Members of the EU Parliament and the Challenge Cancer **Intergroup**

## **2.9 Big Data and Digital health**

Duration: June 2022 – December 2022

### **Context**

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

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

In 2021, ECPC has brought its contribution to the two stakeholder consultations presented by the European Commission on the establishment of the EU Health Data Space (EHDS). The creation of a European Data Space is high on the 2019-2025 Commission agenda and is said to include the health sector. The scope of

setting a common European Health Data Space is to promote better exchange and access to different types of health data (electronic health records, genomics data, data from patient registries etc.). The EHDS will not only support healthcare delivery, but it will also be designed for health research and health policy making purposes.

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

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

### **Objectives**

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

### **Actions**

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

### **Deliverables**

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

### **Timeframe**

- Month 6-9: Survey design and implementation
- Month 9-10: Evaluation of the survey results
- Month 10-12: Presentation of the survey results in an EU Parliament event
- Month 10-12: Publication of the survey results



## 2.10 Cancer and Inequalities

**Duration:** June 2022 – December 2022

### Context

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

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

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

### Objectives

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

Despite several initiatives at EU level, such as the European Partnership for Action Against Cancer (EPAAC) and the Joint Action on Cancer Control (CanCon) where the White Paper directly informed select CanCon recommendations for the development of national cancer plans. ECPC is working with the oncology community to drive implementation of the CanCon recommendations through initiatives such as the Innovative Partnership for Action Against Cancer (iPAAC) and is building the evidence base for the capacity-building of ECPC member organisations' policy and advocacy capabilities. The White Paper 'Challenging the Europe of Disparities' also remains a powerful resource for shedding light on inequalities faced by cancer patients in Member States.

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

### **Actions**

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

ECPC will run a raising awareness social media campaign and will organise an online webinar for patient organisations and other relevant stakeholders and a broader workshop within 2022 . ECPC will also organize national trainings or workshops to raise awareness at country level and among specific disadvantaged groups. We will also provide more detailed guidance on cancer inequalities in their countries and seek input from members in countries where more effective plans are implemented, as good practices can be shared.

### **Deliverables**

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

### **Timeframe**

- Month 6-9: Literature review implementation
- Month 9-10 Social media campaign

- Month 9-10: Online webinar for patient organisations and other relevant stakeholders
- Month 11: Workshop for patient organisations and other relevant stakeholders
- Month 7-12 National trainings to activate member patient organisations

## 2.11 Palliative and complementary care

**Duration:** June 2022 – December 2022

### Context

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

Palliative complementary care could help improve the holistic approach to treatments, meaning seeing the patient as a whole and its surroundings as part of the treatments as well. To improve quality of life, it needs to be a consideration of the patients' day to day routines, stress levels and emotions as well as the molecular chemistry of the patient from a medical point of view. Meditation, Yoga and other complementary care practices may have an impact on stress levels which, in turn, can also improve treatments adherence and outcomes. Treating patients should not only be based on dosage of medicines but should also consider the patients with multi-disciplinary teams that look at all the aspects that the patient needs to be treated in order to better feeling and even improving adherence and outcomes of medical treatments.

### Objectives

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

### Actions

ECPC will try to put the person-centred palliative and complementary care model into the spotlight of the EU agenda by creating a working group putting all relevant stakeholders together to explore the current situation in Europe, new thinking,

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

### **Deliverables**

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

### **Timeframe**

- Month 6 Establishment of a working group
- Month 6-8 Preparation of the campaign and the factsheets
- Month 9-10 EU Parliament event

## **2.12 Cancer Mission**

### **Background**

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

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

### **Importance to Cancer patients**

This specific mission is addressing all types of cancer in all phases. That means from prevention of risk factors to survivorship support and end-of-life care. It is a European Union project meaning it is spreading across all EU Member States. This affects and include patients with rare cancers, patients who are children, adolescence, adults, and old people. Socially and economically vulnerable families

and people living in remote areas are also considered. When understanding a bit better the processes and factors that could lead to cancer, actions on prevention, treatment and quality of life can be improved.

### **ECPC Actions**

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

## **2.13 Europe's Beating Cancer Plan**

### **Background**

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

On February 4th 2021, on the occasion of the World Cancer Day, The Commission published the Europe's Beating Cancer Plan, set to be a "key pillar of a strong European Health Union". The Cancer Plan presents a new EU approach to cancer prevention, treatment and care by making use of new technologies, research and innovation. The plan considers the entire cancer pathway, from prevention to quality of life of cancer patients and survivors, proposing specific actions and targets where the EU can add the most value.

In September 2020, the Special Committee on Beating Cancer (BECA) has begun its one year mandate (currently prolonged till December 2021). In this sense, thirty three MEPs from all political groups engaged to develop a report aimed at presenting to the European Commission their vision for a common framework of cancer treatment in the EU. The rapporteur is the French MEP Veronique Trillet-Lenoir (Renew Europe). In collaboration with the Cancer Related Complications and Comorbidities and Transforming Breast Cancer Together initiatives, ECPC tabled amendments to the BECA report drafted by the rapporteur. These amendments were shared with a list of MEPs and they were incorporated in the final version of the report.

In the last quarter of 2021, the European Commission open a call for stakeholders to express their interest to join the Thematic Networks of the Stakeholder Contact Group on Cancer Plan. The areas of work of these networks are: 1) Prevention; 2) Early detection, diagnosis and treatment; 3) Quality of life; 4) Research, innovation and digitalisation; 5) Reducing inequalities; 6) Childhood cancer.

### **Importance to Cancer Patients**

The Cancer Plan is structured around 4 key action areas, each very important for

cancer patients. These areas are prevention, early detection, diagnosis and treatment, and quality of life. The plan also consists of 10 flagship initiatives and a series of supporting actions. The Commission will invest €4 billion in tackling cancer. This money comes from different financial instruments, such as EU4Health programme, Horizon Europe and the Digital Europe programme.

Among the most relevant supporting initiatives, we mention:

- A new Knowledge Centre on Cancer aimed at coordinating scientific and technical cancer-related initiatives at EU level.
- Cancer Diagnostics and Treatment for All aimed to be launched in 2021 to support greater sharing of tumour profile data with the aim of optimising cancer diagnosis and treatment and reducing inequalities in access to personalised medicine.
- A Cancer Inequalities Registry which will identify disparities and inequalities in cancer care between Member States and regions. This could include exploring inequalities in access to personalised medicine.

This is part of the Commissioner's initiative to by 2030 reduce premature mortality from chronic diseases, including cancer, by one third. If objectives are met, it means better outcomes for everyone currently living with cancer and anyone who in the future might be diagnosed with cancer when better diagnostic tools and treatments are available.

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

### **ECPC Actions**

ECPC will drive the patient voices in all the four action areas of the EU Beating Cancer Plan. ECPC will help gather the patients voices as well as stand up for those who cannot speak themselves. We will make sure that the patient perspective is always included into developing new strategies in all topics and that any improvement of quality of life for survivors, carers and patients are being developed with the consideration of what is important for the people they are developing it for. In this sense, ECPC will participate and provide concrete input in 5 out of 6 Thematic Networks of the Stakeholder Contact Group on Cancer Plan. ECPC will help disseminate, communicate and educate within their patient organisation networks and other stakeholders.

At the same time, ECPC will continue working with the members of the Challenge Cancer Intergroup and the Cancer Complications & Comorbidities Initiative to monitor and shape the implementation of the Cancer Plan at the national level.

## 3. Health and Research

### 3.1 Big Data and Personalised Medicine

#### 3.1.1 QUALITOP

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

**Type:** Horizon 2020

**Duration:** 2020-2024

The logo for QUALITOP, featuring the word "QUALITOP" in blue capital letters. To the left of the 'Q' is a small blue circular icon with a white stylized 'Q' inside. To the right of the 'P' is a small blue circular icon with a white stylized 'Q' inside.

**Aim:** QUALITOP aims at developing a European immunotherapy-specific open Smart Digital Platform and using big data analysis, artificial intelligence, and simulation modelling approaches. This will enable collecting and aggregating efficiently real-world data to monitor health status and QoL of cancer patients given immunotherapy. Through causal inference analyses, QUALITOP will identify the determinants of health status regarding IR-AEs and define patient profiles in a real-world context. For this, heterogeneous data sources (big data), both retrospective and prospective –collected for QUALITOP from clinical centres in four EU countries—will integrate lifestyle, genetic, and psychosocial determinants of QoL. Using machine learning approaches, QUALITOP will provide “real-time” recommendations stemming from patient profiles and feedbacks via the Smart Digital Platform. Furthermore, an increased visibility on patients’ behaviour, a better IR-AEs prediction, and an improvement of care coordination will help analysing through simulation modelling approaches the gain in cost-effectiveness. Guidelines will be issued over the short and long-term. **Lead Coordinator:** HOSPICES CIVILS DE LYON FRANCE

#### What ECPC does:

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

#### 3.1.2 Instand-NGS4P

**Title:** Integrated and standardized NGS workflows for Personalised Therapy

**Type:** IMI project co-funded by Horizon2020

**Duration:** 2020-2024

The logo for Instand NGS for Personalized Therapy. It features the word "Instand" in blue, "NGS" in large green letters, and "for Personalized Therapy" in blue below it. A blue double helix DNA structure is integrated behind the text.



**Lead Coordinator:** MEDIZINISCHE UNIVERSITÄT - GRAZ, AUSTRIA

**Aim:** INSTAND-NGS4P is an EU-funded Pre-Commercial Procurement (PCP) project for improving cancer patient's benefit from Next Generation Sequencing (NGS) by developing an integrated and standardized NGS workflow. For this, it will compile information from cancer gene testing, pharmacogenetics testing and e-medication in proper presentation to medical doctors for supporting therapy decision making at bedside widely applicable in health systems. The project will define unmet medical and technical needs based on an Open Market Consultation, which lays the foundation for a call for tenders addressing solution providers (companies) to develop their products to better meet user needs. Companies responding to this call will be evaluated regarding their ability to answer these users' needs from design perspective until the product phase.

**What ECPC does:**

ECPC will be strongly involved in education, training and dissemination to the public. For patients: ECPC and FAVO will prepare specific materials with adapted languages to inform patients (minor, adult and their family members) on the activities of the various aspects and stages of the project. This type of material will ensure a better understanding of the clinicians' diagnostics by the patients and potentially by its family members (paediatrics and adult patients). ECPC will be part of the Patient Needs Consensus Board, participating in the monitoring of patient requirements and information during the study and ensuring the ethical management of privacy and security of patients' data.

### 3.1.3 LEGACy

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

**Type:** Horizon 2020

**Duration:** 2019-2022

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



**Lead Coordinator:** INCLIVA Health Research Institute

**What ECPC does:**

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



### 3.1.4 BD4BO PIONEER

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

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

**Duration:** 2018-2023

**Aim:** PIONEER is one of the BD4BO disease-specific projects and serves as the European Network of Excellence for Big Data in Prostate Cancer. The project is using big data to address key knowledge gaps related to screening, diagnosis and treatment of prostate cancer by standardising and integrating already existing big data in clinical trials and electronic health records from diverse populations of prostate cancer patients across different stages of the disease into a single, innovative data platform. PIONEER is working for meaningful improvement in clinical practice, improved health outcomes and increased health-system efficiency by providing evidence-based data, so patients can benefit from the best possible care. **Lead Coordinator:** University of Aberdeen



#### **What ECPC does:**

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

### 3.1.5 Lifechamps

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

**Type:** Horizon 2020 Project

**Duration:** 2020-2022

**Lead Coordinator:** Aristotle University of Thessaloniki, Greece



**Aim:** LifeChamps delivers a novel, context-aware and large-scale analytics framework capable of delivering multi-dimensional Quality of Life (QOL) support to all the different cancer life champions during and after their treatments. LifeChamps is providing support to middle aged and older (pre-frail and frail) cancer patients, as well as their caregivers and healthcare professionals, with an integrated Big Data-driven solution capable of improving their QOL via a timely and more accurate clinical decision support at the point of care. Its Artificial

Intelligence (AI) and analytics engine, running both at the cloud and at the mobile edge, can determine accurately which factors affect the oncological patients' QOL the most, during and after their treatment. Furthermore, complemented by a health recommender system LifeChamps offers personalised healthcare services (such as symptom monitoring, treatment and rehabilitation) to these patients and their caregivers. Finally, a multi-factorial frailty model will allow the stratification of sub-clinical frail groups of geriatric cancer patients towards more personalised treatment.

#### **What ECPC does:**

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

### **3.1.6 T2EVOLVE**

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

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

**Duration:** 2021-2025



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

**Aim:** Immune cells that are empowered by gene-engineering to seek and destroy cancer cells (engineered T cell therapy) constitute a transformative novel treatment that has the potential to cure cancer. Multiple new versions of this therapy are being developed for distinct types of cancer but their introduction into clinical practice is hampered by a lack of standardized and validated models to predict safety and efficacy, customized manufacturing and monitoring to scale up production and clinical use to industry standard, and strategies for optimal patient conditioning. The T2EVOLVE consortium unites scientists and physicians, regulators and policy makers, SMEs, and patient stakeholders to tackle these challenges in an orchestrated multi-disciplinary multi-stakeholder approach. A core feature of this approach will be the embedding of patient stakeholders as contributing members of the team across all levels of the R&D process. The overall aim is the development of an innovation ecosystem that will accelerate the process of developing engineered T cell therapy in the EU. The project will deliver novel tools for education and for improving the communication between healthcare providers and patients, optimized laboratory models that can help determine how safe and effective new therapies with engineered T cells are, standardized methods in which these therapies are produced and monitored during treatment. The consortium members are innovators and pioneers in this field that are dedicated to bringing the EU to the forefront of the global engineered

T cell therapy movement. This effort will ensure that EU citizens will continue to have access to the most innovative and best-available medical care, provide guidance on how to implement this novel treatment into the EU health care system in a sustainable way, and secure a leading role for Europe in this emerging field in medicine and science, the economy and society.

#### **What ECPC does:**

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

### **3.1.7 Intervene**

**Title:** International consortium for integrative genomics prediction

**Type:** Horizon 2020 Project

**Duration:** 2021 – 2025

**Lead Coordinator:** UH-FIMM, University of Helsinki



#### **Aim:**

The aim of the INTERVENE project is to develop and test next generation tools for disease prevention, diagnosis and personalised treatment by utilizing the first US-European pool of genomic and health data. The project aims to integrate longitudinal and disease-relevant omics data into genetic risk scores. If successful, the potential for prediction, diagnosis and personalised treatments for complex and rare diseases will be unprecedented. This project will demonstrate the potential and benefits of powerful AI technologies on the next generation of integrative genetic scores (IGS).

#### **What ECPC does**

WP5 AI solutions in clinical setting (4 PM):

- Task 5.2: To evaluate the clinical and economic impact of using polygenic risk information for decision support and primary prevention of breast cancer. (FIMM, UNITO, HUS, UNISI, ECPC) (M1-M60).
- Task 5.2.4 Counselling first-degree relatives of breast cancer patients (FIMM, UNITO, HUS, UNISI, ECPC) (M36-M60)

WP6: Ethical and legal framework for AI and genetics (10 PM)

- Task 6.2: Qualitative assessment of perception of genetic scores and genetic reporting tool (TUM, BBMRI, VUMC, UTARTU, ECPC) (M12-M48)
- Task 6.3: Framework for trustworthy AI and Ethical guidance principles for genetic score-based risk prediction and personalised medicine (TUM, BBMRI, ECPC) (M48-M60)

## WP 7: Project Coordination and Management (10 PM)

- Task 7.1: Internal project management and coordination (FIMM, ECPC, TTOP) (M1-M60).
- Task 7.2: Coordination of the periodic technical and financial reporting (FIMM, ECPC, TTOP) (M1-M60).
- Task 7.5: Planning and hosting of project meetings (FIMM, ECPC, TTOP) (M1-M60)

## WP8: Dissemination, exploitation, and sustainability of the project outcomes (30 PM)

- Task 8.1 Co-creation of a communication and dissemination plan (FIMM, ECPC) (M1-M6)
- Task 8.2: Communication and dissemination activities (FIMM, ECPC) (M1-M60)
- Task 8.6: Plan for exploitation of project results (FIMM, ECPC, TTOP) (M1-M60).

### 3.1.8 TIGER

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

**Type:** Horizon 2020 Project

**Duration:** 2021-2025

**Lead Coordinator:** ETHERNA IMMUNOTHERAPIES (eTheRNA)



**Aim:** TIGER delivers proof of principle (PoP) in humans for a novel best-in-class mRNA cancer vaccine platform optimized for intravenous (IV) administration, with the aim to show major clinical efficacy. The antigens used for the PoP consists of mRNAs encoding the proteins E6 and E7 of Human Papilloma Virus strain 16 (HPV16), and TriMix mRNAs that stimulate dendritic cells to start strong T cell responses. The mRNAs will be formulated in a novel patented lipid nanoparticle format shielding the mRNA, and delivering it to immunoactive antigen presenting cells, vastly enhancing T-cell response. Safety and best-in-class efficacy of our IV mRNA product have been demonstrated in rodent experiments. Furthermore, preclinical to clinical translation has been shown for our TriMix based vaccines using different delivery strategies. Based on the preclinical and prior clinical data, our platform has the potential to cure cancer patients. The PoP study will be in patients with recurrent HPV16 positive cancer, which is categorised as a non-communicable disease by the WHO, without and with a PD-1 checkpoint inhibitor. Safety, immunogenicity and clinical benefit will be key endpoints of the study. Biomarker and PROM research will allow future informed therapeutic and care decisions by both patient and care team. Recruitment and stratification plans will be in place. Interactions with regulatory, reimbursement and ethical authorities together with patients and carers will help laying out the route to the patient not only for our product but also for all other mRNA cancer vaccines. Additionally, the project encompasses all essential elements for preparing therapy validation

in later stage clinical studies, while addressing patient needs, values and choices. Upscaling mRNA vaccine GMP-production will enable these further clinical studies. Once validated, our platform will be easily translatable to a wide range of cancers using other tumour antigens, be they TAAs or neoantigens.

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

## 3.2 Patients and Caregivers

### 3.2.1 PREFER

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

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

**Duration:** 2016-2022

**Lead Coordinator:** Uppsala University



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

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

### 3.2.2 DIAdIC

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

**Type:** Horizon 2020 Project

**Duration:** 2019-2023

**Lead Coordinator:** Vrije Universiteit Brussel



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

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

## 3.3 Palliative Care

### 3.3.1 Palliative Sedation

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

**Type:** Horizon 2020 Project

**Duration:** 2019-2023

**Lead Coordinator:** Radboud University Medical Centre



**Aim:** The Palliative Sedation project aims to test the concept of proportional PS, where sedatives are titrated to the point of symptom control, with the goal of improving the patient's overall comfort.

The project is investigating current practices and guidelines, as well as conducting a clinical study into PS, measuring patient comfort as the primary outcome, which is being carried out at five European palliative care centres. Furthermore, the Palliative Sedation project is formulating recommendations for an updated framework for the use of sedation in palliative care, working towards producing a free online educational programme and an e-book, and helping organise a policy workshop for further development and implementation, along with a closing conference to support the final dissemination of project results.

**What ECPC does:**

ECPC sits on the Palliative Sedation Scientific, Clinical and Ethical Advisory Board to encourage policy-makers, researchers, doctors and industry to recognise cancer patients as co-creators of their own health. ECPC directly engages with expert patient representatives to ensure that research is designed and adapted to better respond to patient needs. Through its members, ECPC contributes to a PS country survey and supportive interviews that reveal the level of integration of

clinical sedation guideline recommendations in healthcare practice across Europe. ECPC also supports the revision of the current European Association for Palliative Care (EAPC) framework for PS, and the design of the PS educational programme and e-book containing clinical and ethical guidance that can be adopted for PS. ECPC will partner the dissemination of the project outcomes to patients, general public, industry and policy-makers.

## 3.4 Treatments

### 3.4.1 Immune-Image

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

**Type:** Funding from the Innovative Medicines Initiative 2 Joint

**Duration:** 2019-2024

Lead Coordinator: Amsterdam UMC



**Aim:** Project will develop methods to visualize and study the immune cells involved before, during, and after such treatments allowing selection of the right treatment for the right patient and at the right time. The information obtained about the immune cells and their activity during disease could be used to develop new drugs that might help those patients for which current immunotherapies are ineffective.

#### What ECPC does:

ECPC supports communication and dissemination of the Immuno-Image project's outcomes towards cancer patients and cancer organisations during the duration of the whole project. This involves conveying information about the trials to confirm safety and to evaluate the clinical potential of novel immune-tracers to ECPC cancer patient community and other relevant European patient organisations. ECPC will also be involved in the management and regulation of data storage and analysis enablement. ECPC involves multiple patient organisations who would benefit from the project outcomes.

### 3.4.2 ImmunoSABR

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

**Type:** Horizon 2020 Project

**Duration:** 2017-2023

**Lead Coordinator:** Universiteit Maastricht (UNIMAAS)



**Aim:** The main objective of ImmunoSABR will be to obtain clinical proof of concept for our bi-modal curative treatment strategy, by conducting a randomised phase II clinical trial in patients with less than 10 metastases from Non-Small Cell Lung



Cancer. We hypothesized ImmunoSABR will prolong progression-free survival (PFS) while maintaining quality of life and at the price of only mild, transient toxicity.

**What ECPC does:**

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

## 3.5 Scientific Committee and Advisory Role

### 3.5.1 EUCANCan

**Title:** European-Canadian Cancer Network

**Type:** Horizon 2020

**Duration:** 2019-2022

**Aim:** EUCANCan aims at supporting and enhancing modern oncology, by implementing a cultural, technological and legal integrated framework across Europe and Canada, to enable and facilitate the efficient analysis, management and sharing of cancer genomic data.



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

**Lead Coordinator:** Barcelona Supercomputing Center

**What ECPC does:**

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

### 3.5.2 PREDICT

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

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





**Duration:** 2017-2021

**Lead Coordinator:** Maastricht University

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

**What ECPC does:**

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

### 3.5.3 HTx

**Title:** Next Generation Health Technology Assessment to support patient-centred, societally oriented, real-time decision-making on access and reimbursement for health technologies throughout Europe  
**Type:** Horizon 2020 Project

**Duration:** 2019-2023



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

**Lead Coordinator:** Utrecht University

**What ECPC does:**

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

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

## 4. Capacity Building

### 4.1 Knowing our Members

#### 4.1.1 Update and development of a professional database

**Duration:** 6 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 6 Start of the project
- Month 6 Hiring or identifying and briefing a person to contact each member (2 months)
- Month 7-8 Quality check
- Month 6-10 Developing the database (6 months)
- Month 11 Delivering the database populated with updated information
- Month 11 Testing the database and troubleshooting
- 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:** 6 months

#### **Context**

Currently ECPC communicates with its members during the Annual Congress, the General Assembly, via mailings, the newsletter, ad hoc requests and on social media. These actions are not enough to gather feedback on ECPC support to its members and to create a constructive dialogue.

#### **Objectives**

Having an in-depth knowledge of all its members' needs, specificities and interests, will radically improve ECPC's legitimacy to accurately represent its members and to become a stronger association and will help strengthening ECPC membership identifying members' strengths, challenges and needs.

#### **Actions**

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

#### **Timeframe and milestones**

- Month 6 – 8 Dissemination of the questionnaire to members
- Month 9 Analysis of the answers
- Month 10 – 12 Drafting the report and recommendations

#### **Deliverables**

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

## 4.2 Bonding with our Members

### 4.2.1 ECPC Conference

**Duration:** 4 months

#### **Context**

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

building and networking. In 2022, we will organize hybrid form of the ECPC Conference.

### **Objectives**

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

### **Actions**

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

### **Timeframe / milestones**

- Month 4 Venue selection
- Month 4 Starting accommodation booking
- Month 4 Draft programme and promotion of the event: 2 months before
- Month 5 Press relations: 1 month before

### **Deliverables**

- Conference agenda
- Conference report

## **4.2.2 General Assembly**

**Duration:** 6 months

### **Context**

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

- Fostering a relevant, democratic and dynamic NGO, faithfully representing its members

- Showing them its work and the upcoming challenges
- Putting to vote important decisions such as the budget, the action plan, statutes changes, main political and strategic directions

In 2020, the General Assembly was held virtually on the 21<sup>st</sup> of November and in 2021 on the 27<sup>th</sup> of November. Thus, for the 2022 edition, a hybrid form will be organized in 28<sup>th</sup> May 2022, in Brussels Belgium.

### **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 3-4 Sending a mailing of information
- Month 3-5 Collecting questions through mailings, social media and on the website and promoting the Live Q&A video: two months prior to the event + reminders every two weeks and then every week
- Month 5 Live Q&A video: 2 weeks before the event

### **Deliverables**

## 5. Communications and Awareness Campaigns

### 5.1 Make Sense of head and neck cancer campaign

Head and neck cancers are the 6<sup>th</sup> most common types of cancer in Europe with more than 150,000 new patients diagnosed every year. There is little awareness among the public with many cases diagnosed at a late stage. Despite major advance in the treatments of head and neck cancer over the past decades including new surgical tools and radio therapeutic modalities, the overall patient outcomes remain disappointingly unchanged.

#### Rationale

It has been observed that there is a significant lack of awareness of head and neck cancer in Europe. According to a pan-European survey conducted among the general public, 77% of respondents were unaware of the term 'head and neck cancer'. This survey also highlighted that there is a lack of knowledge among the general public of the risk factors, signs and symptoms of head and neck cancer, demonstrating a clear need for further education. As a result of this lack of awareness, it is unsurprising that nearly two thirds of all head and neck cancers are diagnosed at an advanced stage and 10% of patients show metastases at distant sites from the first presentation.

In recent developments, the release of RARECARE data sheds a new light on head and neck cancers which involve several anatomically diverse sites (e.g. oral cavity, pharynx, nasal cavity and sinuses) which are rare. The disease is complex, needs multimodality treatment, and the patient population is more likely to be elderly and have comorbidities and less social support. The study explores unsolved problems for rare cancers. Thus, the results suggest that diagnosis and treatment of head and neck cancers did not reach optimal standards in the EU countries considered in the study. Most head and neck cancer patients are still diagnosed at advanced stage, experienced delay in starting the treatment and are not treated with multi therapy.

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

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

#### Objectives

Objectives of the 2022 project are the following:

- To **raise awareness**, through a social media campaign and a webinar, of head and neck cancer across Europe among the general public and healthcare professionals in order to improve outcomes through earlier diagnosis and treatment
- To highlight the link between the **HPV and head and neck cancer** and communicate the need for action to slow the growing numbers of HPV-related head and neck cancers
- To emphasize the fact that **smoking and drinking** can greatly increase the risk of developing head and neck cancer.
- To communicate the **discrepancies in care between Member States** and the need for adoption of standardised guidelines into national cancer plans – EHNS Head and Neck Cancer Survivorship guidelines (that should be launched in 2022) and ESMO multidisciplinary care Head and Neck guidelines
- To explore among relevant stakeholders how to best implement the **survivorship guidelines** at a national level using the updated White Paper on Head and Neck Cancer and factsheets
- To **promote research** into technology and medicines that aid the screening, vaccination and treatment of head and neck cancer.

### Head and Neck Fact Sheets

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

### Head and Neck Cancer Awareness Week

The social media campaign with impactful image and video messages of patients will be launched on social media during the Head and Neck Cancer Awareness Week (September 2022 ) to raise an awareness of the disease and to increase the attention of policy makers towards the topic. ECPC will develop a call to action dedicated to policymakers which will be distributed to members of the European Parliamentary Intergroup on Cancer, “Challenge Cancer” Intergroup, other Members of the European Parliament and to the European Commission Team working on the Europe’s Beating Cancer Plan just before the launch of the campaign. At the same time, the updated factsheets and its translations will be distributed among ECPC members and stakeholders, general practitioners and the general public.

### Webinar on Head and Neck cancer

With the cancer mission naming cancer a top EU priority for the European Commission and the European Parliament, and the ongoing coronavirus health crisis that is directly and indirectly affecting outcomes of cancer patients’ treatments and diagnosis, it is vital that head and neck cancer remains high on the European agenda. As such, this event seeks to raise awareness about the disease

and to address the objectives mentioned, through also launching **a call to action of six key action points** that we want to seek support for:

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

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

### **Survivorship Guidelines**

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

### **Deliverables**

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



- Guidelines for HNC patients co-developed with patients to secure the patient perspective

### Timeline

- **June-July:** identify patients and stakeholders to involve directly in the project, identify the content for updating the fact sheets
- **July:** organise focus group to update the fact sheets
- **June – August:** finalisation of materials, translations and graphic layout of any relevant materials for the campaign
- **June - September:** Preparation and implementation of the awareness campaign

## 5.2 Fundraising – communications (toolkit)

**Duration** 2 years

### Context

ECPC Members have different profiles from very small scaled organisations to nationally reputable federations. The diversity of their situation is reflected in their financing model and volume of resources available. Fundraising is one of the main challenges ECPC members face.

### Objectives

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

### Actions

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

### Timeframe / milestones

- Month 6-7 Writing and laying out fact sheets
- Month 9-12 Organising webinars: June 2022 September 2022, June 2023, September 2023

- Month 6-12 Articles on best practices all year long

### **Deliverables**

- Webinar report/s

## **5.3 Nutrition**

**Duration:** June 2022 – December 2022

### **Context**

Nutrition is a crucial component of cancer treatment and rehabilitation as it helps patients better cope with illness. However, given the focus on the cancer and its cure, nutrition is often neglected, leaving patients and their families with doubts, questions and the need for practical guidance on how to eat better on a daily basis, especially during therapy.

In 2015 ECPC developed a pilot survey on nutrition and its importance on the treatment and life of cancer patients. As preliminary data suggested that discrepancies existed between patients' expectations and the answers they receive from physicians, a second survey was developed in 2016. A total of 907 patients and survivors were surveyed in 10 European countries including: Finland, Italy, Spain, Czech Republic, Greece, Denmark, Slovenia, Romania, Poland, and Bulgaria. The results were presented at the 2017 Annual Congress and at ESMO and a booklet was launched in November.

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

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

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

### **Objectives**

- To inform and empower patients on the importance of nutrition during their cancer treatment and after cancer
- To raise awareness of the importance of Nutrition among policy makers at national and EU level

### **Actions**

Nutrition and Physical Activity Awareness Month is celebrated every year in

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

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

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

### **Deliverables**

- National events
- Updated version of Series II of the “Living well During Cancer Treatment Nutrition Patient Booklet”

### **Timeframe**

- Month 6-9: Update Nutrition and Physical Activity materials and organisation of the social media campaign
- Month 6-9: Updated version of Series II of the Living well During Cancer Treatment Nutrition Patient Booklet
- Month 6-12: National Events

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

**Duration:** June 2022 – December 2022

### **Context**

Twenty years ago, when cancer treatments were very toxic and mortality was higher, if a patient had asked the oncologist if physical activity was good during treatment, the advice would have been to avoid physical exertion and to preserve the strength to deal with treatments.

Already in 2012, several studies showed the following:

- Walking is a workout that can be practiced without difficulty by most cancer patients.
- Even home walking exercises are an effective intervention for patients

suffering from various types of carcinoma (including breast, pancreas and lung cancer).

- Cancer patients who continue to train even after diagnosis have a lower risk of mortality and recurrence and that exercise reduces the number and intensity of side effects (peripheral neuropathy, fatigue, depression, sleep disorders, cardiovascular toxicity, existential and psychological distress).

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

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

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

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

## **Objectives**

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

- Breaking down the cultural and organizational barriers that prevent the treatment team from recommending physical activity to patients and patients to consider exercise as an ally during and after cancer
- Including physical exercise in clinical practice as a therapy
- Including sport among the useful recommendations for a return to a normal, active and productive life after cancer

## **Actions**

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

- A literature review on the latest scientific evidence to support the relationship of physical activity and cancer treatment and survival

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

### **Deliverables**

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

### **Timeframe**

- Month 7-10: Conduction of the literature review
- Month 9-10 Update of informative brochure on physical exercise & sport
- Month 9-10: Preparation of the awareness campaigns
- Month 11-12: Awareness campaign

## 6. Strategic Alliances

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







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