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1 INTRODUCTION

The voice of Europeans with cancer

The European Cancer Patient Coalition is the voice of people with cancer in Europe. With over 400 members, its vision is for a Europe of equality, where all European people with cancer have timely and affordable access to the best treatment and care available. ECPC will work towards this vision by influencing the European political agenda, empowering and educating its members, and increasing the role of patients in cancer research.

ECPC's 2018 achievements

In 2018, ECPC actively participated in the review of the European Commission's Proposal for a Regulation on Health Technology Assessment, and launched a new online educational module on Health Technology Assessment.

Based on the ECPC White Paper on Cancer Carers, ECPC carefully reviewed the European Commission's proposed Directive on Work-Life Balance for Parents and Carers, and collaborated with several Members of the European Parliament to submit a number of amendments. These amendments focused on the formal recognition for carers, the importance of paid leave, and the value of flexible working conditions.

The Coalition continued its work on the Joint Action on Rare Cancers, mapped and produced rare cancer patient material, contributed to the European Reference Networks, and joined the European Commission's Innovative Partnership Action Against Cancer (iPAAC).

The Coalition held a clinical trial workshop for its Members on collaboration with the European Organisation for the Research and Treatment of Cancer. It was also active member in four Horizon 2020 projects, three Innovative Medicines Initiative projects, two Innovative Training Networks, and one Seventh Framework Programme project.

The scientific paper, "Perception of Nutritional and Metabolic Derangements in Patients With Cancer and Cancer Survivors" under publication in the Journal of Cachexia, Sarcopenia and Muscle. Based on the results of this research, the Coalition led a European Nutrition and Physical Activity Awareness Campaign, and launched its "Living well with Cancer" educational booklet.

The Coalition also worked with its Members on bladder cancer, supportive care, cancer-associated thrombosis, head and neck cancer, pancreatic cancer, and personalised medicine.

The Coalition's ultimate mission is to listen to its Members and represent them at the European level. The Coalition welcomed 185 participants to its Annual Meeting, and consolidated its position as Europe's largest cancer patient association, with a total of 445 Members. Each one of its Members are essential for the work of the organisation.

ECPC Strategy

ECPC Board's 2016-2019 strategy is based upon four pillars:

- **Governance:** build a sustainable model for governance and cooperation with its Members
- **Policy:** influence the EU legal framework and the European and national political agenda
- **Capacity building:** empower cancer patient organisations to shape national policy and strengthen their abilities to serve cancer patients
- **Research:** increase the role of people with cancer in research

ECPC Objectives

The main objective of the 2018 Action Plan was to consolidate the role of ECPC as the main voice of cancer patients in Europe. In order to uphold this commitment, the organisation worked to ensure that the patient perspective had a strong role in initiatives care such as EU Joint Action on Rare Cancers and Innovative Partnership Action Against Cancer. New high-quality education materials supported the advocacy and educational efforts of the Members of the coalition on topics such as Merkel cell carcinoma, cancer-associated thrombosis, and nutrition. These materials were also translated into multiple languages in order to facilitate communication and understanding.

The two main objectives of the 2019 Action Plan are to strengthen the connections with Members, and ensure organisational continuity during the transition from the 2016-2019 to the 2019-2021 Board in June. Once the new Board has begun its mandate, it will work with the Secretariat to develop the European Cancer Patient Coalition strategy for 2019-2021.

Capacity-building initiatives

ECPC exists to serve its Members. Building the capacity of ECPC's Members improves the capability of patient organisations to develop, implement, and advocate for patient empowerment at the national, regional, and global level. ECPC is as strong as the bond between the organisation and its Membership.

Throughout 2017, the Membership of the European Cancer Patient Coalition increased to 445 organisations. This is a clear demonstration of the increasing trust that more and more patient's organisations place in ECPC.

For ECPC to maintain such trust, it is necessary to keep providing Members with quality services and to increase such services to better respond to the needs of cancer patients' organisations on the field. For this reason, ECPC will invest time and resources to increase and potentiate capacity building initiatives towards its membership, and empower them to share best practices.

The 2019 capacity-building objectives are to welcome at least 200 participants to our Annual Congress, and to ensure that all relevant materials are translated into multiple languages in order to facilitate communication and understanding, such as the online educational modules for immuno-oncology therapies and health technology assessment.

Focus on key policy issues for people with cancer

ECPC's speciality and main mission remains to be the voice of people with cancer in Europe. To do so, ECPC will continue to follow and to contribute to a variety of policy issues at the European level.

In 2019, ECPC will focus on developing the main policy themes:

- Europe of social disparities for cancer patients (see Section 4.2);
- health technology assessment (see Section 2.1);
- patient-centred research (see Section 6);
- support for rare cancers (see Sections 2.2, 4.8, 6.1).

At the same time, ECPC will explore new policy topics of interest, in relation to the outcome of the three-years strategy. The policy objective for 2019 is to confirm ECPC's commitments undertaken in 2018 and to keep following the main EU policy files for 2019, such as Health Technology Assessment, the Work-Life Balance Directive, the European Pillar of Social Rights, the implementation of the recommendations of the second Joint Action for Cancer Control (CanCon) such as the harmonisation and implementation of national cancer plans, and the new third Joint Action for Cancer Control (iPAAC).

Developing and consolidating partnerships

Between 2013 and 2018, ECPC consolidated its relationship with several other non-government organisations, and built new bridges with new non-government organisations. Among others, the results from the collaborations ECPC has established with the European Society for Medical Oncology, European Society for Surgical Oncology, the European Society for Radiotherapy and Oncology, and the Cancer Drug Development Forum will ripen in 2019, contributing to a compelling pack of joint initiatives.

The objective for 2019 is to build upon the established partnerships in order to ensure that these initiatives serve the needs of the Members of ECPC.

Research

Research projects allow ECPC to be on the forefront of scientific developments. ECPC works to ensure that the patient perspective is heard and respected, while improving scientific knowledge about cancer. ECPC emphasises the importance of involving patients as co-researchers and strongly advocates for the best partnership model between both researchers and patients, allowing patients to contribute their unique experience working towards a more patient-centric study while participating in crucial project decisions.

In 2019, ECPC will continue to contribute to European research projects, as well as joining consortia to bid on future projects to begin in 2020.

ECPC is currently involved in three IMI projects (PREFER patient preferences, DO-IT Big Data for Better Outcomes, PIONEER Big Data for Prostate Cancer), six H2020 projects (LEGACy gastric cancer, DIadIC psychosocial interventions, IMMUNISA cervical cancer, ImmunoSABR metastatic lung cancer, H2020MM04 DENIM mesothelioma, Transcan-2 European research area), one FP7 project (eSMART mHealth symptom management), and two Innovative Training Networks (ELBA liquid biopsies, PREDICT radiomics).

In 2019, ECPC will organise the final events celebrating the completion of the DO-IT Big Data for Better Outcomes project and the eSMART mHealth symptom management project.

Governance

The European Cancer Patient Coalition derives its mandate to speak with "one voice" for all people with cancer from its wide membership and its democratic structure. Good governance is vital because the organisation needs to be run well in order to last, as well as to retain and attract new Members and supporters. Without good governance, the organisation will cease to

exist. The objective in 2019 will be to develop the governance processes and transparency in decision-making. The Board will work with the office to improve the decision-making processes, transparency, meeting procedures, working deviation and co-operation.

In 2018, the General Assembly of ECPC voted to update the organisation's statute. The ECPC Board, with the support of the Audit Committee and office, invested efforts to make sure that ECPC continues to grow as a sustainable governance-model organisation that is able to represent its valuable members in the most efficient way.

ECPC's aim is to make sure that it follows the most recent requirements and administrative trends for non-profit organisations registered under Belgian law, that will compliment and correspond well with our main activities and goals.

In line with this mission, the 2018 General Assembly approved the ECPC General Regulations to formalise the role of the Scientific and Audit Committee, the Office, the Board, and the Working Groups. The Regulations are a milestone for the European Cancer Patient Coalition, and are a picture of the current situation of ECPC. They are a reference for the ECPC Board and a guide for the future.

In addition, the ECPC Statute was updated to ensure that British members retained full membership after Brexit, as well as members located within European Free Trade Association. To underline their value, associate members were given the right to join ECPC Working Groups, contribute to ECPC projects, and apply for ECPC patronage of their events. To ensure continuity of expertise, the Immediate Past President will become the Chair of the Scientific Committee and a non-voting member of the Board.

The new 2018 Statute and General Regulations can be downloaded from the ECPC website at: www.ecpc.org

Furthermore, ECPC will work to increase its dialogue with its Members. A Members survey will be launched at the 2019 Annual Congress, in order to identify the priorities of European cancer patient organisations. Furthermore, a member of the 2019-2021 Board will be given responsibility to work with the Community and Communications team to interact with Members, boost collaboration, and build a well organised "listening system".

The European Cancer Patient Coalition action plan outlines the main proposed activities for 2019. The activities are divided into:

- **Educational projects** designed to educate people with cancer and patient organisations about issues that are important to them. They are a balance of online and face-to-face projects that distil and simplify complex information, and make it understandable and accessible.
- **Awareness campaigns** designed to increase the awareness of cancer-related issues. They use the power of social media, as well as public events if necessary, to reach their target audiences.
- **Policy and Advocacy projects** relate directly to ECPC's mission to represent Europeans with cancer and to ECPC's capacity to raise awareness on key policy issues affecting people with cancer. In 2019, ECPC will focus on Health Technology Assessment, the Work-Life Balance Directive, and the Europe of Social Disparities;
- **Capacity-building activities** are Pan-European efforts designed and implemented to provide ECPC's Members with the necessary skills to conduct cancer advocacy, as well as with European added value in their daily fight against cancer. These are projects aiming at empowering ECPC's members to add cancer policy advocacy to their activities and at providing them with new instruments to help people with cancer;
- **Health and Research programmes** allow ECPC to be on the forefront of the European Union's health and scientific developments on cancer, providing the patients' perspective in European programmes.

The Coalition has the direct, experienced and voluntary support of ECPC's Board and Members in the development and implementation of all activities of the Action Plan.

For each project, ECPC prepares an accurate budget following the principle of full cost recovery.

Calendar of activities for 2019

- January
 - European Prostate Cancer Awareness Day
- February
 - World Cancer Day
- March
 - Nutrition and physical activity awareness month
 - Patient advocacy session at European Association of Urology congress
 - International HPV Awareness Day
- May
 - Bladder cancer awareness month
 - European Parliament elections
- June
 - European Cancer Patient Coalition Annual Congress
 - The 2019-2021 ECPC Board begins its mandate
 - Cancer Survivors Day
- July
 - Joint Action on Rare Cancers Steering Committee meeting (to be confirmed)
- September
 - iPAAC Joint Action stakeholder forum (to be confirmed)
 - European Society of Medical Oncology congress
 - Make Sense of head & neck cancer awareness campaign
- October
 - IMI PREFER Patient Preferences Annual Meeting (to be confirmed)
- November
 - Pancreatic cancer awareness day
 - Personalised medicine awareness month campaign

2 EDUCATION

2.1 Health Technology Assessment (ongoing, pending)

Board champions: Francesco De Lorenzo, Kathi Apostolidis, Andrew Winterbottom, Ken Mastris

Staff responsible: Head of EU Affairs

Health technology assessment is the method used to measure the value of a new medicine, medical device or procedure compared to the existing options. The assessment examines the direct and intended effects of this technology, as well as its indirect and unintended consequences. It is used by countries and regions to decide if a medication or medical device is a cost-effective way of treating a disease. Increasingly, cancer patient organisations are being given the opportunity to contribute to the health technology assessment of oncology treatments.

In the last decade, there have been marked advances in the medical therapy of many different types of cancers. Many of these new cancer therapies may offer benefits in terms of overall survival, improved quality of life, or improved safety. Society must ask if the extra cost of these cancer therapies, compared to existing therapies, is the most cost-effective way of investing these funds. With limited healthcare resources, society may get greater value by investing some of these funds elsewhere.

Although innovation in oncology treatments has contributed to improvements in therapy, the magnitude of the benefits to people with cancer can vary widely. Health systems must examine each treatment separately, and decide on the cost-effectiveness of each treatment by examining the survival, quality of life, and safety of the new treatment compared to the existing treatments.

Today, very few HTA agencies in Europe involve patients in their assessments and where public engagement is sought, the approaches vary. The European Commission's proposal seeks to dismantle barriers to involving patients in Health Technology Assessment, by creating established methods for providing patient evidence. However, to date, the progress made in the European Parliament on the HTA legislative file, does not provide for adequate patient participation in the new EU HTA cooperation framework. Cancer patients are the most important partners in the fight against cancer and all cancer-related challenges affecting our society today. Considering that they are the ultimate beneficiaries of innovation in medical technologies, patients' needs, and preferences must be captured, when assessing the value of new therapies.

In 2018, ECPC launched an online educational module for cancer patients on Health Technology Assessment, increasing knowledge and confidence for ECPC Member Organisations to participate in Health Technology Assessment at national level, advocate for it where there are no established frameworks for patient involvement in HTA. Building on the online educational module, ECPC will

establish and facilitate peer-to-peer mentoring programmes for patient organisations seeking to exchange knowledge and first-hand experiences from participation in Health Technology Assessment.

In 2019, ECPC will focus on updating, translating, communicating, and disseminating this educational module. Additionally, ECPC will work together with its members to identify existing tools and materials that can be directly used by patient organisations in Health Technology Assessments, such as templates for appeal mechanisms and expressions of interest.

The HTA “Buddy-up” Programme will be an extension of HTA eLearning Module and an onboarding and knowledge sharing method to link theoretical knowledge to real-world examples. ECPC will launch a call for interest for members seeking to further develop their knowledge and expertise on patient involvement in Health Technology Assessment. In a form of a Working Group, interested ECPC members will be joined by patient advocates from ECPC Member Organisations with more experience in HTA.

The mentoring programme will involve assigning one (or more) members to a “buddy” who will guide them following the Working Group meeting. The programme will establish a formal documented process that outlines responsibilities of both parties but will maintain the necessary flexibility. The buddy-system will encourage both parties to share knowledge, tips, tools and techniques from their experiences.

Mentoring programme in the Working Groups and one-to-one in person or remote mentoring would include:

- Sharing different aspects of the experiences of involvement in HTA
- Answering questions in the Working Group Meeting or remotely
- Provide information, guidance to information available elsewhere and informal support
- Introducing members to other connections who may be helpful to their development
- Encourage them to ask questions if unsure about any aspects of patient involvement in HTA

ECPC would provide secretarial support, organise the Working Group meetings and facilitate one-on-one exchange, where necessary. As part of the mentoring programme, ECPC would develop a guide for both “buddies” to facilitate learning and help members to make the most of the experience.

Implementation

ECPC will work with oncology and patient education experts to translate its interactive online educational module focusing on the health technology assessment of cancer treatments, map other useful tools, and promote these resources.

Deliverables

- Updating, translating, communicating, and disseminating the interactive online educational module on Health Technology Assessment of cancer treatments
- Mapping of other tools that can be used by patient organisations in Health Technology Assessments
- Online awareness campaign promoting module and tools
- HTA “Buddy Up” programme for patient organisations

Timeframe

- Month 0: Funding confirmed
- Month 1: Project kick-off
- Month 2: Confirm languages
- Month 3: Translations
- Month 4: Development of communication materials
- Month 5: Expert Review
- Month 6: Finalise the translations and communication materials
- Month 7: Implementation and testing
- Month 9: Launch the translated website
- Month 10: Launch of the event and communication campaign
- Month 11: Communication campaign

Evaluation

The success of this project will be measured by:

- Number of people using the module
- Proportion of participants saying that they would recommend this module to a friend
- Feedback from Members

2.2 Rare cancer patient information & cross-border healthcare (ongoing, pending)

Board champions: Francesco de Lorenzo, Jana Pelouchova

Staff responsible: Head of Health and Research Programmes

As part of its ongoing work to support people with rare cancers, ECPC is working to identify, produce, and disseminate patient information on rare cancers. ECPC is looking for suggestions from its Members for patient guides that they would find useful.

This project would also be linked to the Joint Action on Rare Cancers (Section 4.8) and the European Reference Networks (Section 6.1), and build upon ECPC's work to develop educational tools and learning programmes for the rare cancer patient communities. ECPC will also work to ensure that Europeans affected by cancer have all the current information about the European Reference Networks, and their nearest Centre of Excellence. On its website, ECPC will publish all information to ensure that cancer patients can take advantage of all the information and expertise that the European Reference Networks have to offer.

ECPC will also advocate for the increased support and implementation of the European Reference Networks, in order to ensure the long-term sustainability of this initiative, beyond the lifetime of the Joint Action on Rare Cancers.

The Cross-Border Healthcare Directive was widely welcomed by the patient community and gave hope to many patients seeking better healthcare abroad. It was a great success to have the Joint Action on Rare Cancers and the European Reference Networks approved by Member States, especially EURACAN (the European Reference Network for rare adult solid tumours). The Joint Action on Rare Cancers will optimise the creation of the European Reference Networks by providing them with guidelines for harmonisation, operational solutions, and professional guidance in the areas of quality of care, epidemiology, research and innovation.

However, despite the first European Reference Networks being launched in 2017, we are seeing little change on the ground. Substantial administrative and economic barriers remain to cross-border care, meaning that the Directive is not yet truly serving people affected by rare cancers. Currently, there are very few rare disease patients within Europe who know how to access the centres of excellence within their country.

To this end, ECPC has written a letter to the European Commission to call for mechanisms facilitating the sustainability and implementation of the European Reference Networks, and to ensure the Joint Action on Rare Cancers recommendations are fully implemented. This will ensure that Europeans with rare diseases receive the full benefits of the European Reference Networks.

Objective

To improve Europeans' understanding of particular rare cancers and their access to European Reference Networks and Centres of Excellence.

Deliverables

- Letter to the European Commission calling for implementation of Joint Action on Rare Cancer recommendations and sustainability of the European Reference Networks
- Development of educational tools and learning programmes for the rare cancer patient communities
- Online education webpage on particular rare cancers for people with cancer and their family (2,500 words)
- Printable tri-fold A4 leaflet on particular rare cancers to be disseminated during events related to rare cancers (500-700 words)

Implementation

Website: ECPC will collaborate with European experts in order to produce information on particular rare cancers, in order to create an area on the European Cancer Patient Coalition educational section of the website. The webpage will include information on causes, risk factors, warning signs, states, treatment options, and prevention guidelines. ECPC will also publish information on all the European Reference Networks related to rare cancers and a list of all the Centres of Excellence in each country.

Leaflet: The material will also be summarised into a printable tri-fold A4 leaflet to be disseminated during events related to rare cancers.

Joint Action on Rare Cancers: see Section 4.8

European Reference Networks: see Section 6.1

Timelines:

- January: Contract with industry partner signed
- February: Project kick-off
- March: Drafting of materials
- April: Expert review of content
- May: Social media calendar drafted
- June: Website content sent for translation
- July: Social media calendar approved
- August: Review of translations
- August: Final approval of website content
- September: Website created
- October: Month-long social media communication campaign launched
- October: Website officially launched
- November: Final approval of brochure content
- November: Brochures sent for translation
- December: Brochures launched

Evaluation

The success of this project will be measured by:

- Number of people visiting the website
- Number of downloads of leaflet
- Engagement on social media
- Number of leaflets distributed during events

2.3 Nutrition and physical activity (ongoing, pending)

Board Champions: Francesco de Lorenzo, Kathi Apostolidis, Jana Pelouchova

Staff responsible: Head of Health and Research Programmes

Nutrition and physical activity are crucial components of cancer treatment and rehabilitation as it helps people to better cope with the illness. However, given the focus on the cancer and its cure, nutrition and physical activity are often neglected, leaving people with cancer and their family with doubts, questions and the need for practical guidance, especially during therapy.

ECPC, in collaboration with nutrition experts, developed a survey and scientific paper on nutrition, based on empirical data, which was presented at the 2017 Annual Meeting, the 2017 ESMO congress, and is under publication in the Journal of Cachexia, Sarcopenia and Muscle. The results from the survey showed a substantial gap in terms of need for information and practical management of cancer-related nutritional problems for people with cancer. The paper provided a solid basis for the development of patient friendly information material on nutrition.

In November 2017, MEP Daciana Octavia Sârbu (S&D, Romania), in collaboration with ECPC, hosted an event in the European Parliament on the important topic of the Role of Nutrition in Cancer Care. The event witnessed the launch of the Consultation Document which was adapted to the "Living Well During Cancer Treatment" booklet. In this booklet, survey results from the ECPC survey were presented together with "questions to ask your Oncologist", key messages, and a proposed Cancer Patient's Charter of Rights for Appropriate and Prompt Nutritional Support for adaption at EU level. The "Living Well During Cancer Treatment" booklet was endorsed by the European Society for Surgical Oncology.

Also in November 2017, the European Pillar of Social Rights was proclaimed by President Juncker, which includes nutrition, health and education, and is linked to the European Commission's proposed Work-Life Balance Directive for Parents and Carers.

In March 2018, ECPC promoted the importance of nutrition and physical activity during a month-long advocacy campaign. This initiative featured a strategic Pan-European awareness-raising campaign, "#RecipeAgainstCancer", with MEPs and health stakeholders' engagement. ECPC also created the "Nutrition and Physical Activity Awareness Month Toolkit" to provide guidance to its Members on how to join and support the campaign. A substantial translation service was carried out and communications materials were made available in ten different languages.

In 2019, ECPC will further build on previous work done by translating the "Living Well During Cancer Treatment" booklet into multiple languages and promote the Charter of Rights at the National level through organising national events. It will also continue its collaboration with the European Society

for Surgical Oncology to ensure that guidelines for surgery and nutrition are disseminated throughout Europe. ECPC will also lead the March 2019 Cancer and Physical Activity Awareness Month.

Implementation

The month of March is Nutrition and Physical Activity Awareness Month, where we stand together to increase the awareness of the importance of nutrition and physical activity for all people with cancer. The management of nutrition and physical activity is becoming increasingly important for people with cancer, especially as survival and quality of life is increasing. The evidence-based Guidelines will be translated into simple messages that will be disseminated using a social media campaign. Building upon the materials it developed in 2018, ECPC will promote the Nutrition and Physical Activity Awareness Month toolkit for patient organisations. This toolkit will include a Thunderclap, Twibbon, and social media calendar. A Social Media Thunderclap allows a single message to be mass-shared, so it rises above the noise of the social networks. By boosting the signal at the same time, Thunderclap helps organisations create awareness. One message, one number, one date. It's a common aspiration for all supporters of better nutrition and physical activity for people with cancer.

In 2019, ECPC will further build on previous work done by translating the Nutrition Booklet into multiple languages and promote the Charter of Rights at the National level through organising national events.

Deliverables

- Translation of “Living Well During Cancer Treatment” booklet into different languages
- Printing of “Living Well During Cancer Treatment” booklet into different languages
- National events

Timeframe

January 2019: Nutrition and physical activity awareness month toolkit released

February 2019: Translation of “Living Well During Cancer Treatment” booklet begins

March 2019: Nutrition and Physical Activity Awareness Month

October - December 2019: National events

Evaluation

The success of this project will be measured by:

- Number of people visiting the website
- Number of downloads of “Living Well During Cancer Treatment” booklet
- Number of “Living Well During Cancer Treatment” booklet distributed during national events

2.4 ecancer-ECPC biosimilar online module (new, confirmed)

Board Champions: Maude Andersson, Ken Mastris

Staff responsible: Partnerships & Communication Manager

Goal:

- To improve the awareness and understanding of oncology biosimilars within European cancer patients
- To improve awareness and understanding of the potential issues around communicating the use of biosimilars for healthcare professionals treating cancer patients in Europe

Objectives:

The objectives of this project are to:

- Increase understanding of the current situation and improve levels of understanding of oncology biosimilars within European cancer patients
- Create an educational portal for cancer patients and patient organisations within the ECPC website (ecpc.org) to that hosts a series of educational resources developed specifically for cancer patients in English, French, German, Italian and Spanish
- Distribute the educational resources to patients across Europe through ecancer's patient focused website www.ecancerpatient.org as well as through ecancer's YouTube channel
- Create a series of educational resources for healthcare professionals with a focus on improving clinical practice when treating patients with oncology biosimilars

As many biosimilars come to market in the next several years, their use in oncology will play an important role in the future care of patients with cancer. Biosimilars present a necessary and timely opportunity for physicians, patients and healthcare systems. If suitably developed clinically, manufactured to the correct standards and used appropriately, they can positively impact on the financial sustainability of healthcare systems. Biological medicinal products form an integral and effective part of the management of non-communicable and communicable diseases. They are crucial to treating life-threatening conditions in all disease areas, including oncology. Currently, there is an inconsistent approach to biosimilars across Europe, while pricing policies and instruments to enhance the uptake of generics are advanced, the surveyed countries appear to be struggling to find the most appropriate approach for biosimilar medicines. Biologics play an integral role in the treatment of cancer not only for their therapeutic effects and ability to improve outcomes and the education of physicians and other healthcare providers, payers, and patients about biosimilars may facilitate informed decision making, promote acceptance of biosimilars into clinical practice, increase accessibility, and expedite associated health and economic benefits.

As the American Society of Clinical Oncology recognise in their statement on biosimilars in oncology, continuous provider education is critical to inform, promote, and use biosimilar products in a medically appropriate and cost-effective way to treat cancer. Also important is patient education about biosimilars provided by a knowledgeable health care professional. Public awareness and education, and the use of standardised, publicly available materials from professional societies, government sources, and patient advocacy groups will help to ensure understanding of biosimilars. Given the novelty of biosimilar development and its reduced emphasis on clinical testing, there is greater need for education among providers regarding biosimilar products and their appropriate use.

Target Learner Audience:

The primary audiences for this project are:

- Cancer patients in Europe with a particular focus on those from the target countries
- Healthcare professionals treating patients with cancer in the target countries

The existing resources available for patients online are mainly in pdf format which don't offer an engaging educational experience. ecaner and ECPC propose to build upon these existing resources by reviewing their content and updating with the latest developments in the field of biosimilars and convert the information into engaging multi-media content which enhances understanding and knowledge retention for patients.

ecaner, in consultation with ECPC, will develop a series of multimedia educational resources for patients with video content hosted within an environment where patients can control the pace of their progression through the materials. A transformation of any information provided by oncology professionals is needed to bridge the gap caused by the differences in knowledge and terminology between physicians and patients. This can be addressed by the provision of contextual information such as explanations and demonstrations and providing lay summaries which help to create a common ground and significantly increase patient understanding.

Information provided to patients will be in short snippets to enhance information retention therefore the content we produce will focus on delivering short videos of information which the patients can absorb and progress from at their own pace. The content will also be limited to one or two key messages per section to enhance information understanding and retention.

Patients' understanding of medical information is also seen to be improved if the information is structured and interactive. Interactivity seems to be especially important, educators should provide an interactive approach that allows users to tailor for themselves the amount and type of information they receive. Patients learn better from multimedia when messages are designed in ways that are consistent with how the human mind works and with research-based principles, we will therefore base all our resources on the latest standards in this area.

The final programme of resources will be developed alongside the educational committee of this project; however, topics will include:

- What is a biosimilar medicine - background and history
- What is the evidence that biosimilars are effective medicines?
- How are biosimilar medicines approved in Europe and who decides on the availability?
- What impact do biosimilars have on treatment decisions?
- What's my role as a patient in the decision-making process?
- If I am already being treated, should I switch to a biosimilar?
- Additional Sources of Information

Patients will be able to create personalised 'print out and keep' sheets that they are encouraged to take to a consultation with their physician to assist with discussions around any future treatment decisions. There will be drag and drop functionality where patients will be able to include the key terms and topics that are important to them as well as a free-text field for true personalisation. These sheets will then be printable and saveable for the individual patient's future reference.

ECPC will host the resources in an educational portal similar to our existing Immuno-oncology portal as shown here on the home page of their website. The portal we develop will provide information in multiple languages for patients. With engaging and interactive use of animation and other visual tools to explain the key concepts. The information will be designed to all of the latest multi-media and patient communication best practice guidelines as outlined above.

As well as being hosted on the ECPC website, it will also be hosted on ecancer's patient focused website www.ecancerpatient.org which receives 2,200 video views from patients across Europe per month and through ecancer's YouTube channel which receives an average of 3,500 video views per month in Europe.

ECPC will be involved in the development of a robust dissemination and communication plan to ensure engagement of the public and patients during the implementation and post-implementation phase of the project with promotional materials developed in local languages where appropriate, including creating a visual identity, development of multiple social media platforms, and building an effective external stakeholder network including activity such as including information on the educational portal in three newsletters. We will also distribute the resources to ecancer patient's audiences through inclusion in the quarterly newsletter (570 registered members) and through our Twitter (824) and Facebook (102) channels as well as promoting the resources through targeted YouTube and Google AdWords advertising campaigns for appropriate searches.

3 AWARENESS

3.1 HPV Awareness Day (ongoing, confirmed)

Board Champion: Maude Andersson

Staff responsible: Partnerships and Communication Manager

Over 80% of people will be infected by human papillomavirus virus (HPV) at some point in their life. While some types of HPV may not have any symptoms and visible signs, there are a few that can harm us and our loved ones. The most harmful HPV types cause cervical, anal, oral, penile and other deadly cancers. The good news is that there are solutions. By increasing awareness and taking preventative measures, we can make the world a safer place for everyone.

ECPC is a sustaining partner of International HPV Awareness Day, 4 March, as part of the organization's commitment to raising awareness of HPV-related cancers. Through this annual campaign, ECPC works with the International Papillomavirus Society and its Member to promote progress on HPV prevention, screening and management of HPV related diseases.

Objectives

- Increase public awareness of the importance of HPV prevention, screening and management
- Advocate for HPV vaccination for males and females
- Advocate for further research on HPV

Implementation

During International HPV Awareness Day in on 4 March 2019, ECPC will work with the International Papillomavirus Society and its Member to increase public awareness of the importance of HPV prevention, screening and management. It will also advocate for HPV vaccination for both males and females. ECPC will develop a social media calendar for the 4 March, based on Social Media Toolkit developed by the International Papillomavirus Society.

Deliverables & Timeframe

- 4 March 2019: International HPV Awareness Day

Evaluation

The success of this project will be measured by social media engagement.

3.2 Make Sense of head and neck cancer campaign (ongoing, pending)

Board Champion: Jana Pelouchova

Staff responsible: Partnerships and Communication Manager

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

ECPC is a partner in the Make Sense Campaign, working with the European Head and Neck Society, to advocate for better awareness of head and neck cancers. In 2013, ECPC and the European Head and Neck Society published a White Paper on Head and Neck cancer, which advocated for increased awareness, better prevention & treatment, standardised care, and better quality of care and quality of life after diagnosis.

As part of the September 2019 Make Sense Campaign, with its continuing theme of Survivorship, ECPC will organise an event in Brussels to promote awareness of these cancers and call for prevention, standardised care, and better quality of life for people with cancer and cancer survivors.

Implementation

Event in Brussels discussing head and neck cancers

Proposed topics: Survivorship, radiotherapy, immuno-oncology therapy

Timeframe

- June 2019: Preparations begin
- September 2019: Press release and event in the European Parliament

Evaluation

The success of this project will be measured by:

- Number of people attending the event
- Proportion of positive responses from people who complete the event survey
- Traditional media engagement about the event
- Social media engagement about the event

3.3 Prostate Cancer Awareness Month (ongoing, confirmed)

Board Champion: Ken Mastris

Staff responsible: Partnerships and Communication Manager

Prostate Cancer is on the rise and the most frequent cancer in men. It is the third most common cause of death in men in Europe, with important consequences for healthcare systems. Saving lives and ensuring a high quality of life requires immediate European actions.

ECPC, the European Association of Urology and Europa Uomo (the European Prostate Cancer Federation), work together to increase the awareness of prostate cancer and call for change.

In 2017, the White Paper on Prostate Cancer was launched by Europa Uomo, European Cancer Patient Coalition and the European Association of Urology. The White Paper outlined the next steps to lower the risks and improve the management and care of prostate cancer. This launch was followed by an event in the European Parliament during Prostate Cancer Awareness Month in September 2017. During this meeting, representatives from ECPC spoke about the role of patients and civil society in health promotion and prevention campaigns.

In 2018, during the European Association of Urology congress in Copenhagen, a representative from ECPC spoke at the "EAU Patient Information Session" and asked the European Union to help sustain awareness of pancreatic cancer, provide the means to improve both diagnosis and treatment, and support equity of management for all.

Objectives

- Increase public awareness of the importance of prostate health
- Educate about risk factors and symptoms of prostate cancer
- Advocate for further research on prostate cancer

Implementation

In 2019, ECPC will establish a Urological Cancers Working Group, to bring together all its members interested in improving outcomes for people with urological cancers.

On 22 January 2019, an event at the European Parliament will be held for European Prostate Cancer Awareness Day. This event aims to raise awareness, understanding and knowledge of the management of prostate diseases in general and prostate cancer in particular. By joining forces during a yearly event, key policy makers, scientific associations and European patient groups review and discuss how to change the management of prostate cancer across Europe to provide a more holistic and personalised tailored care for patients. ECPC is a collaborating partner of European Prostate Cancer Awareness Day.

The issue of Prostate Cancer will again be featured at the "EAU Patient Information Session" during the European Association of Urology congress in Barcelona from 15-19 March 2019. The Fira de Barcelona will host Europe's largest annual event showcasing the latest and the most relevant science in the urological field. ECPC will co-host a Patient Advocacy Session at the European Association of Urology congress in Barcelona on Sunday 17 March from 13:45 until 16:45, in collaboration with Fight Bladder Cancer UK and Europa Uomo.

During Prostate Cancer Awareness Month in September, ECPC will work with Europa Uomo and the European Association of Urology to increase public awareness of the importance of prostate health, educate about risk factors and symptoms of prostate cancer, and advocate for further research on prostate cancer. ECPC will develop a social media calendar for the month of September, based on Prostate Cancer Awareness Month Social Media Toolkits developed by the GW Cancer Institute and the Men's Health Network.

A representative from ECPC will speak at an event in the European Parliament to mark European Prostate Cancer Awareness Day (EPAD). Policy makers, scientific experts, European associations working in the urological field and representatives of European patient groups with an interest in prostate disease will come together for this event. The next steps to lower the risks and improve the management and care of prostate cancer will be discussed by key influencers in both the political and scientific arena.

ECPC will also use the month of September to promote the work of the Innovative Medicines Initiative PIONEER project, of which it is an active partner. The PIONEER project is using big data for better outcomes in prostate cancer (Section 6.4)



Deliverables & Timeframe

- March 2019: Presentation on Prostate Cancer at the European Association of Urology congress
- September 2019: Prostate Cancer Awareness Campaign
- September 2019: European Prostate Cancer Awareness Day event in the European Parliament

Evaluation

The success of this project will be measured by social media engagement.

3.4 Personalised Medicine Awareness Month (ongoing, pending)

Board champions: Francesco de Lorenzo, Jana Pelouchova

Staff responsible: Head of EU Affairs

One important component of personalised medicine is biomarker testing, which includes molecular testing. This is used to diagnose early stage cancers, improve the accuracy of prognosis, and predict how well a patient will respond to a particular treatment.

In 2016, ECPC carried out a biomarkers survey from people with cancer, in collaboration with the European Alliance for Personalised Medicines, and found that biomarkers are still largely unknown by people with cancer and are insufficiently used by physicians. Lack of reimbursement for biomarker testing in many European countries creates an obstacle for improving clinical outcomes for people with cancer.

In 2017, ECPC hosted a policy roundtable in the European Parliament together with Member of the European Parliament Marlene Mizzi (Socialists & Democrats, Malta). Titled “Biomarkers in the Era of Personalised Medicine”, the event brought together patients, policy-makers, researchers and the industry to discuss the importance of biomarkers for people with cancer, and the necessary actions needed to make precision medicine in cancer a reality across Europe.

In 2018, ECPC produced a detailed webpage and infographic on biomarkers. The infographic was available as an animation, website and downloadable pdf. ECPC also joined the Genomics Work Package (WP6) of the Innovative Partnership Against Cancer (iPAAC), which will focus on develop practical guidance for member states on important aspects in successfully integrating genomics in the health care system (see Section 4.7 of the ECPC Action Plan).

In September 2018, ECPC held an event in Brussels in collaboration with the Cancer Drug Development Forum, and in November 2018 led a month-long advocacy campaign across Europe called “Cracking the Cancer Code”, empowering ECPC Members to promote the importance of access to cancer biomarker testing and molecular testing. This campaign also provided educational messages for healthcare professionals, patients, and patient organisations.

ECPC collaborated with the International Quality Network for Pathology, the Cancer Drug Development Forum, and the European Alliance for Personalised Medicines to translate the importance of biomarker and molecular testing into simple messages for people with cancer that were disseminated using a social media campaign.

Objectives:

- To promote the importance of cancer molecular testing and other types of biomarker testing
- To raise awareness of the important role that cancer molecular testing and other types of biomarker testing plays in cancer treatment
- To raise awareness and understanding of the importance of molecular testing and other types of biomarker testing

Implementation

Building upon the campaign and educational materials it developed in 2018, in 2019 ECPC will produce an updated Personalised Medicine Month toolkit for patient organisations. ECPC will partner with an agency to produce a toolkit that includes a Thunderclap, Twibbon, and social media calendar using the hashtag #PersonalisedMedicineMonth. A Social Media Thunderclap allows a single message to be mass-shared, flash mob-style, so it rises above the noise of the social networks. By boosting the signal at the same time, Thunderclap helps organisations create action and change like never before. One message, one number, one date. It's a common aspiration for all supporters of personalised medicine for people with cancer.

Following the advocacy campaign during the Personalised Medicine Awareness Month in November 2018, ECPC will maintain momentum and reach out directly to the audiences we intend to influence (policy makers, regulators and payers) while continuing to share relevant information on personalised medicine with patients - via patient groups - and healthcare professionals. The focus of the Personalised Medicine Month Advocacy will be on creating opportunities to directly engage with relevant policy and /regulatory stakeholders in order to drive regulatory change.

ECPC will bring together key stakeholders - including patient advocates, general practitioners, oncologists, nurses, academia, payers and insurers - at a round table meeting in the European Parliament, to garner support and identify tangible steps to facilitate a future of truly personalised healthcare that is available for all. This event will also be linked to the launch of the updated Immuno-Oncology Policy Action Framework (Section 4.4)

A report of the roundtable policy meeting will be developed and disseminated to partners. ECPC is in a position to build a vital bridge between these disparate groups, ensuring continued dialogue that drives meaningful change.

Deliverables

- Personalised medicine awareness month toolkit
- Awareness campaign
- Roundtable event
- Session on biomarkers and molecular testing at the ECPC Annual Congress
- Roundtable outcomes report

Timeframe

- June 2019: Personalised Medicine month toolkit
- November 2019: Personalised Medicine Month
- November 2019: Event in the European Parliament
- December 2019: Outcomes report

Evaluation

The success of this project will be measured by:

- Number of people attending the event
- Proportion of positive responses from people who complete the event survey
- Traditional media engagement about the event and awareness month
- Social media engagement about the event and awareness month

3.5 Pancreatic Cancer Campaign (ongoing, confirmed)

Board champions: Kathi Apostolidis, Matti Järvinen

Staff responsible: Partnerships and Communication Manager

World Pancreatic Cancer Day

World Pancreatic Cancer Day occurs each year in November. ECPC will support and amplify World Pancreatic Cancer Day by developing a social media calendar to schedule messages on and around World Pancreatic Cancer Day, joining the World Cancer Pancreatic Day Thunderclap on Twitter, and promoting World Cancer Day in the News section of the European Cancer Patient Coalition website.

Pancreatic Cancer Europe

ECPC is a Board member of Pancreatic Cancer Europe. ECPC chairs the work stream that coordinates and supports national activities, as well as the uptake of the materials produced by Pancreatic Cancer Europe. With coordinated actions at national level designed to raise awareness and increase early diagnosis we will work to ensure that pancreatic cancer is "forgotten no more". The Director of the European Cancer Patient Coalition will be a speaker at the Pancreatic Cancer Europe meeting at the European Parliament in 2019, and will present the discuss about the European activities around World Pancreatic Cancer Day, and about the dissemination of the materials developed by the Pancreatic Cancer Europe at the national level.

Timeframe

- June 2019: Pancreatic Cancer Europe General Assembly
- November 2019: World Pancreatic Cancer Day
- November 2019: Pancreatic cancer event in Brussels
- December 2019: Publication of the World Pancreatic Cancer Day report.

Evaluation

The success of this project will be measured by:

- Number of people attending the event
- Proportion of positive responses from people who complete the event survey
- Traditional media engagement about the event and awareness month
- Social media engagement about the event and awareness month

4 POLICY & ADVOCACY

4.1 Manifesto and Handbook for new MEPs (new, pending)

Board champions: Francesco de Lorenzo, Kathi Apostolidis, Matti Jarvinen

Staff responsible: Head of EU Affairs

ECPC has a long history of working with Members of the European Parliament to ensure that the voice of Europeans with cancer is heard within the European Parliament. Following the European Elections in 2019, hundreds of new Members will be joining the European Parliament, many for the first time.

At the European Union level, the European Pillar of Social Rights, the Joint Action on Rare Cancers, the Cross-Border Healthcare Directive, the European Reference Networks, and the proposed EU Cooperation on Health Technology Assessment and Work-Life Balance Directive provide a framework for Member States to take action to protect the rights of people with cancer and their carers.

The European Parliament has a champion in advocating for equality and social justice - ECPC. The 2019 European Parliament elections come at a turning point for the European Union, which needs to reconnect with its citizens and represent their needs and interests. ECPC advocates for a forward-looking European Union where not only economy and growth matter, but where cost-effective action is taken to ensure that everyone affected by cancer can have access to the best possible support, treatment and care.

ECPC will work with a consultancy to produce a manifesto to be released before the elections, and an infographic and an informative MEP Handbook to be produced after the elections.

The manifesto will be a one-page document that highlights the importance of overcoming inequalities, and provides recommendations to MEP candidates to help enforce the rights of people with cancer and their carers to appropriate cancer prevention, care, and treatment. It will also emphasise the importance of nutrition, physical activity, social rights, EU cooperation on Health Technology Assessment, European Reference Networks, work-life balance, and returning to work. The manifesto will be translated into all EU languages, and promoted by ECPC and its member organisations. ECPC will assist its member organisations to adapt the manifesto to reflect country-level concerns, and will ask MEP candidates to express their support for the manifesto.

After the EU elections have been completed, ECPC will produce a handbook which will be sent to all elected MEPs. With the handbook, ECPC will brief the new Members of the European Parliament about the importance of public health in European legislation. It will also aim to highlight the need for action at the EU level on cancer, and empower MEPs with the knowledge of the challenges people with cancer face every day across the European Union today.

ECPC will use the MEP Handbook as a basis for building new relationships and policy partnerships with new Members of the European Parliament, as well as fostering the existing ones.

This handbook will answer the following questions:

- Why is cancer important?
- What are the current challenges associated with cancer?
- What are the current challenges associated with cancer?
- Why is EU public health important?
- What is the European Cancer Patient Coalition?
- How has the European Cancer Patient Coalition improved European policy?
- What has the European Parliament achieved in cancer and health policy?
- What do Europeans with cancer need from MEPs in 2019?

Deliverables

- ECPC EU election manifesto
- ECPC Handbook for MEPs

Evaluation

The success of this project will be measured by:

- Number of handbooks distributed
- Number of meetings with MEPs
- Number of MEPs who agree to work with ECPC to improve EU health policy

4.2 Europe of Social Disparities White Paper (new, pending)

Board Champions: Francesco de Lorenzo, Kathi Apostolidis, Matti Järvinen

Staff responsible: Head of EU Affairs

In 2015, the European Cancer Patient Coalition published a Position Paper titled “Challenging the Europe of Disparities in Cancer”. Developed together with researchers, academia and other organisations, the position paper aimed at pointing out principal causes of inequalities in cancer care in Europe, in particular highlighting the factors which can be tackled at the EU level with concrete policy recommendations.

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

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

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

ECPC will also work with a consultancy to undertake a legal analysis and expert consultation on the legally established provisions in the areas of social protection (such as inability/disability recognition), social benefits, employment rights, access to loans and insurance, amongst others. The report will seek to identify the differences that exist amongst the member states in legal protections for people with cancer and their carers and identify key policy recommendations which could be implemented at the EU-level to bring greater equality to all European citizens and reduce the burden of social disparities.

In producing this paper, ECPC will collaborate with other oncology stakeholders, such as the European Organisation for the Research and Treatment of Cancer (EORTC), the European Association of Urology (EAU), Eurocarers, the European Society for Medical Oncology (ESMO), European Society for Radiotherapy & Oncology (ESTRO) and the European Oncology Nursing Society (EONS) to ensure that multiple perspectives are addressed.

ECPC will also work with European Organisation for Research and Treatment of Cancer (EORTC) to develop a peer-reviewed paper that will be submitted to the Journal of Cancer Policy for publication.

ECPC will also use the Europe of Social Disparities White Paper as a basis for building new relationships and policy partnerships with new and returning Members of the European Parliament, in order to advocate for greater commitment and European policy action to bring uniform social and employment protection for people with cancer and their carers.

The Europe of Social Disparities White Paper will be linked to several European initiatives, such as the Right to Work MEP Focus Group, the European Work-Life Balance for Parents and Carers Directive, and the European report on “Pathways for the reintegration of workers recovering from injury and illness into quality employment”.

Right to Work MEP Focus Group

The new MEP Focus Group launched by MEP Rory Palmer (UK) together with ECPC, joins together over 20 Members of the European Parliament and a number of European stakeholder organisations. The group aims to secure better protection for employees who have been diagnosed with a serious illness. As a first step, the group aims at collecting more research into the situation on the ground in different EU countries, encourage EU employers to sign a ‘voluntary charter’ and eventually introduce new EU legislation to protect employees diagnosed with a serious illness. In 2019, following the European elections, ECPC will work towards continuation of the MEP Focus Group, with an aim to gain further support and commit new members, towards new EU legislation proposal.

Work-Life Balance for Parents and Carers Directive

One of the deliverables of the European Pillar for Social Rights is an initiative to address the work-life balance challenges faced by working parents and carers. The initiative aims at modernising the existing EU legal framework in the area of family-related leaves and flexible working arrangements. The proposal for a Directive on Work-Life Balance for Parents and Carers includes the introduction of ‘carers leave’ and flexible working arrangements amongst others.

Pathways for the reintegration of workers recovering from injury and illness into quality employment

The own-initiative report initiated by MEP Jana Zitnanska (Slovakia) seeks to encourage the Member States to create comprehensive pathways to facilitate the reintegration and return to work of people after a long-term illness. The report proposes solutions for prevention and early interventions, specific solutions surrounding the return to work and changing attitudes towards reintegration of workers. ECPC supports this report, and is working with Members of the European Parliament to adopt the report and forward the resolution to the European Commission with a mandate to develop a legislative proposal.

Deliverables

- Webpage listing members of the Legal Network for Cancer Patients and their work
- Europe of Social Disparities in Cancer White Paper
- Online awareness campaign promoting “Challenging the Europe of Social Disparities in Cancer”
- Event in European Parliament to launch “Challenging the Europe of Social Disparities in Cancer”

Timeframe

- September-November 2018: Questionnaire on legal provisions in the areas of social protection
- December 2018: Analysis of results from questionnaire
- January 2019: Identification of authors and reviewers of Europe of Social Disparities White Paper
- March 2019: Table of contents
- May 2019: First draft
- May 2019: Review by ECPC members, authors, and reviewers
- June 2019: Second draft
- June 2019: Face-to-face meeting of the Legal Network for Cancer Patients
- June 2019: Session on The Europe of Social Disparities at the ECPC Annual Congress
- July 2019: Review by ECPC members, authors, and reviewers
- October 2019: Final draft
- December 2019: Launch of “Europe of Social Disparities White Paper”
- February 2020: Appointment with Social Affairs Commissioner to present Call to Action
- March 2020: Abstract submission

4.3 Medical use of Cannabis and Cannabis-derived medicines (new, pending)

Board champion: Francesco de Lorenzo, Ken Mastris

Staff responsible: Head of EU Affairs

Cannabis and cannabis-derived products are available in some Member States for cancer patients in the terminal stage of disease and for those experiencing substantial pain. However, there is no harmonised EU legal framework in this area. In 2018, the discussions at institutional level have started in some member states as well as at the EU level. A debate in the European Parliament resulted in a Draft Motion for a Resolution in The Committee on the Environment, Public Health and Food Safety requesting action from the European Commission, to address education and access challenges. The Draft Motion for a Resolution and its amendments were adopted in the Committee and it will be put to a Plenary vote in the European Parliament in December 2018.

In 2019, following the European elections, ECPC will advocate for a harmonised legal framework for the medical use of cannabis and cannabis-derived products in all EU Member States. ECPC will advocate for increased education of healthcare professionals on the legal aspects and potential clinical benefits of medicinal cannabis and cannabis-derived medicines. As one of the few patient organisations directly involved in research, thus bringing patients' perspective in EU Funded Health & Research projects, ECPC will work to highlight the importance for increased research funds in this area.

4.4 Immuno-oncology Policy Action Framework Update (ongoing, pending)

Board champions: Francesco de Lorenzo, Kathi Apostolidis, Ken Mastris, Jana Pelouchova

Staff responsible: Head of EU Affairs

The [Immuno-Oncology Portal \(IOP\)](#) is Europe's first information hub on cancer immunotherapies produced by patients for patients. The Immuno-Oncology Portal responds to the need of people with cancer to understand what cancer immunotherapies are. Since its launch in November 2015, the Immuno-Oncology Portal has collected thousands of visits, affirming itself as one of ECPC's most viewed webpages.

ECPC answered this need in 2017 by creating an Access section on the Immuno-Oncology Portal website. In 2018, ECPC improved the Access section and produced a webpage highlighting the ESMO guide on the unique side-effects associated with immuno-oncology treatments.

In 2019, ECPC will update the "Policy Action Framework on Immuno-Oncology" that was first published in 2014. It will also produce a webpage on combination immuno-oncology and radiotherapy treatment.

In updating this document, ECPC will collaborate with other oncology stakeholders, such as the International Quality Network for Pathology, the Cancer Drug Development Forum, the European Alliance for Personalised Medicines, European Organisation for the Research and Treatment of Cancer (EORTC), the European Association of Urology (EAU), Eurocarers, the European Society for Medical Oncology (ESMO), European Society for Radiotherapy & Oncology (ESTRO) and the European Oncology Nursing Society (EONS) to ensure that multiple perspectives are addressed.

ECPC will bring together key stakeholders - including patient advocates, general practitioners, oncologists, nurses, academia, payers and insurers - at a round-table meeting in the European Parliament, to garner support and identify tangible steps that need taking to facilitate a future of personalised healthcare and better access to immuno-oncology therapy. This event will be linked with Personalised Medicine Month (Section 3.4).

A report of the roundtable policy meeting will be developed and disseminated to partners. ECPC is in a position to build a vital bridge between these disparate groups, ensuring continued dialogue that drives meaningful change.

Implementation

The European Cancer Patient Coalition will work with oncology and patient education experts to update the “Policy Action Framework on Immuno-Oncology” that was first published in 2014 and produce a webpage on combination immuno-oncology and radiotherapy treatment.

Deliverables

- Policy Action Framework on Immuno-Oncology 2019
- Online awareness campaign promoting “Policy Action Framework on Immuno-Oncology 2019”
- Report on annual usage and update of iop.ecpc.org

Timeframe

- Month 0: Funding confirmed
- Month 1: Project kick-off
- Month 2: Identification of authors and reviewers
- Month 3: Table of contents
- Month 4: First draft
- Month 5: Review by ECPC members, authors, and reviewers
- Month 6: Second draft
- Month 7: Review by ECPC members, authors, and reviewers
- Month 9: Final draft
- Month 11: Launch of “Policy Action Framework on Immuno-Oncology”

Evaluation

The success of this project will be measured by:

- Number of visits to the immuno-oncology policy website
- Number of downloads of the “Policy Action Framework on Immuno-Oncology”
- Number of printed booklets distributed
- Number of people attending the launch event
- Proportion of positive responses from people who complete the launch event survey
- Traditional media engagement about the launch event
- Social media engagement about the launch event

4.5 Bladder Cancer Awareness & Policy (ongoing, pending)

Board Champion: Andrew Winterbottom

Staff responsible: Partnerships and Communications Manager

The European Cancer Patient Coalition Paper on Bladder Cancer was launched in April 2016, in collaboration with ECPC members such as Fight Bladder Cancer UK, Action Bladder Cancer UK, and Associazione PaLiNUro Italy.

In 2018, ECPC launched a Bladder Cancer Working Group of international patients and patient organisations passionate about improving awareness and understanding of bladder cancer. The first European bladder cancer patient experience survey was launched, as well as the first European bladder cancer awareness month in the month of May. In 2019, this group will become the Urological Cancer Working Group.

In 2019, ECPC will continue its focus on bladder cancer as it is a common, yet neglected pathology, which dramatically affects the lives of hundreds of thousands of patients across the EU and has a severe impact on European healthcare systems. ECPC will submit the results of the European bladder cancer patient experience survey to a peer-reviewed journal, update the 2016 White Paper on Bladder Cancer, and disseminate these materials to its Members and stakeholders.

Objectives

- To improve the co-operation between people with bladder cancer and patient organizations
- To promote the interests of people with bladder cancer and patient associations
- To enable bladder cancer patient organizations to continue to develop common positions on European health policy

Implementation

Urology Cancer Advocacy Session

ECPC will co-host a Patient Advocacy Session at the European Association of Urology congress in Barcelona on Sunday 17 March from 13:45 until 16:45, in collaboration with Fight Bladder Cancer UK and Europa Uomo. The objective of this meeting is to build the capacity of European prostate, kidney, and bladder patient advocacy groups to support their members and advocate for better care.

Bladder Cancer Awareness Campaign

The month of May is Bladder Cancer Awareness Month. This is a time to remember all those who have lost their fight with this disease, and also to stand together for those currently affected by bladder cancer. Bubbles for Bladder Cancer is an annual event for people across the world, initiated by Fight Bladder Cancer UK. ECPC will work with other bladder cancer organisations, such as the World Bladder Cancer Patient Coalition, to produce a blanket of bubbles in public places and online to call for better awareness and outcomes.

Patient Experience Survey

ECPC will submit the results of the European bladder cancer patient experience survey to a peer-reviewed journal, and update the 2016 White Paper on Bladder Cancer.

White Paper

Some new treatment options have been authorised for advanced bladder cancer in the past three years. ECPC will work with the European Association of Urology (EAU) to update the 2016 White Paper on Bladder Cancer to reflect changes in treatment and policy.

In updating this White Paper, ECPC will collaborate with other oncology stakeholders, such as Fight Bladder Cancer UK, the World Bladder Cancer Patient Coalition, the International Quality Network for Pathology, the Cancer Drug Development Forum, the European Alliance for Personalised Medicines, European Organisation for the Research and Treatment of Cancer (EORTC), Eurocarers, the European Society for Medical Oncology (ESMO), the European Society for Radiotherapy & Oncology (ESTRO) and the European Oncology Nursing Society (EONS) to ensure that multiple perspectives are addressed.

Deliverables

- Urology cancer patient advocacy session report
- Patient experience survey manuscript
- Updated White Paper on Bladder Cancer

Timeframe

- Month 0: Funding confirmed
- Month 1: Project kick-off
- Month 2: Identification of authors and reviewers
- Month 3: Table of contents
- Month 4: First draft
- Month 5: Review by ECPC members, authors, and reviewers
- Month 6: Second draft
- Month 7: Review by ECPC members, authors, and reviewers
- Month 9: Final draft
- Month 11: Launch of “White Paper on Bladder Cancer 2019”

Evaluation

The success of this project will be measured by:

- Number of visits to the bladder cancer website
- Number of downloads of the bladder cancer materials
- Number of printed bladder cancer materials distributed
- Proportion of positive responses from people who complete the survey
- Traditional media engagement
- Social media engagement

4.6 All.Can (ongoing, confirmed)

Board champions: Francesco de Lorenzo, Kathi Apostolidis, Maude Andersson

Staff responsible: Head of EU Affairs

All.Can was set up to engage policymakers on the need to improve the efficiency of cancer care, focusing on better outcomes for patients. Its aim is to identify ways we can optimise the use of our resources in cancer care. All.Can comprises leading representatives from patient organisations, policymakers, healthcare professionals, research and industry. ECPC is represented on the All.Can Steering Committee, as well as the working groups on research and evidence; Communications, events and stakeholder engagement; and national initiatives.

The mission of All.Can is based on the European Commission's Joint Action on Cancer Control (CanCon) "Policy Paper on Enhancing the Value of Cancer Care Through a More Appropriate Use of Healthcare Interventions". Representatives from ECPC were co-authors on this policy paper, and ECPC was a founding member of All.Can.

ECPC Members, such as those in Italy and Greece, are also in the process of national All.Can initiatives. The initial aims of the national initiatives include producing policy reports that put the recommendations of All.Can's international report into the local context, and holding stakeholder events to define priority working areas.

Objectives

- Lead and commission research to gather evidence on where system inefficiencies exist, and help identify ways to improve efficiency in cancer care
- Develop concrete tools and platforms for stakeholders to work together to ensure cancer care decisions are focused on what matters most to patients, and resources are used as effectively as possible
- Help to implement concrete policy actions based on these findings.

In 2019, All.Can will focus on:

- Dissemination activities and targeted communications and calls to action from policymakers based on findings from the All.Can patient survey.
- Further development of national All.Can initiatives and taking key messages from the patient survey to national policymakers
- Continuing data collection and analysis the ICHOM-All.Can study of hospitals
- Launch a Think Piece on the role of data in driving efficiency

4.7 Innovative Partnership Action against Cancer (iPAAC) (new, confirmed)

Board champions: Francesco De Lorenzo, Kathi Apostolidis, Matti Järvinen

Staff responsible: Health and Research Officer

ECPC is the one of the cancer patient organisations involved in the European Commission's Innovative Partnership Action against Cancer (iPAAC), along with Europa Colon and Europa Donna. The iPAAC Joint Action brings together partners from 24 Member States across Europe whose main objectives are to build upon deliverables of the CANCON Joint Action and to implement innovative approaches to cancer control. A Roadmap on Implementation and Sustainability of Cancer Control Actions will be the main deliverable of this Joint Action. ECPC will participate in Work Package 6 (Genomics), Work Package 7 (Cancer Information and Registries), and Work Package 8 (Challenges in Cancer Care). The iPAAC Joint Action has received funding from the European Union in the framework of the 3rd Health Programme, and will run from 2018 to 2021.

Work Package 6 (Genomics)

The aim of Work Package 6 is to develop practical guidance for member states on important aspects in successfully integrating genomics in the health care system. In 2019, ECPC will contribute to the education and training on genomics for citizens and patient organisations, and to the chapter on 'Genomics in healthcare'.

Work Package 7 (Cancer Information and Registries)

The Work Package 7 objective is to enhance population-based cancer information systems to better support evidence-based comprehensive cancer care. In 2019, ECPC will contribute to guidelines on longitudinal integration of administrative health care records and centralised coding systems at national level, advise on selection of informative epidemiological indicators on cancer prevalence and survivorship, and to disseminate results.

Work Package 8 (Challenges in Cancer Care)

Work Package 8 will define strategies to optimise the use of healthcare resources and promote evidence-based responses to existing needs. This work package will examine neglected cancers, pancreatic cancer, criteria for re-organisation of treatment delivery, integration of cancer care, and the economics of cancer care. ECPC will participate in meetings on the definition of neglected cancers and on the clinical variables to describe pancreatic cancer patient pathways. It will advise on addressing patient centred communication and participation in decision making, and examine the need for the integration of palliative care at the time of diagnosis, particularly for life-threatening cancers such as pancreatic cancer. In 2019, ECPC will contribute to recommendations for improving

access to expert clinicians in reference hospitals, reflect patients' concerns regarding diagnosis and treatment of pancreatic cancer, and its potential impact on outcomes.

4.8 Joint Action on Rare Cancers (ongoing, confirmed)

Board champions: Francesco de Lorenzo, Jana Pelouchova, Ken Mastris

Staff responsible: Head of Health and Research Programmes

The Joint Action on Rare Cancers (JARC) is aimed to integrate and maximize efforts of the European Commission and EU Member States to advance quality of care and research on rare cancers. The public health challenge posed by rare cancers combines both the typical problems of rare diseases and cancers where the need of timely diagnosis and access to quality treatment is vital. Accordingly, JARC is shaping its efforts around the [European Reference Networks \(ERNs\)](#): several of which are specifically devoted to rare cancers, have been conceived by the EU Commission as a means to provide “highly specialised healthcare for rare or low-prevalence complex diseases”.

The formal activation of [European Reference Networks](#) is a cornerstone in the EU cooperation on rare cancers, and this Joint Action should be, instrumental to help them evolve by optimizing the process of [ERN](#) creation through the provision of operational support and professional guidance in the areas of quality of care, epidemiology, research and innovation, education and state of the art definition on prevention, diagnosis and treatment of rare cancers. The Joint Action on Rare Cancers and the [European Reference Networks](#) are crucial game changers for rare cancer patients in Europe bringing together scarce knowledge and fragmented resources to maximise synergies and results.

ECPC has written a letter to the European Commission calling for mechanisms to ensure the implementation of the recommendations of the Joint Action on Rare Cancers and the sustainability of European Reference Networks (see Section 2.2).

ECPC represents the needs, rights and hopes of people with rare cancers in the Joint Action on Rare Cancers (JARC): ECPC has a horizontal role representing the voice of the rare cancer patients across all the work packages.

WP number	WP name
1	Coordination
2	Dissemination
3	Evaluation
4	Epidemiology
5	Assuring Quality of Care
6	Clinical practice guidelines
7	Innovation and access to innovation
8	Medical education
9	Childhood Cancers
10	Rare Cancer Policy

In order to better represent the rare cancer patient community, ECPC counts on the expertise and collaboration of rare cancer patient organisations all over Europe. Following the formal request of several rare cancer patient representatives during the European Cancer Patient Coalition Annual Congress 2016, ECPC established a Working Group on Rare Cancers, working in parallel with the Joint Action on Rare Cancers, to guarantee that a large number of rare cancer patient organisations, representing different European countries and rare cancer types, will be able to contribute to the activities of the JARC.

Every ECPC Member (Full and Associate) and non-member active in rare cancers can join the Working Group on Rare Cancers, which will meet in person once a year during the Annual Congress. The Working Group on Rare Cancers also collaborates via an online forum.

Implementation

ECPC will ensure the dissemination of the activities of the Working Group on Rare Cancers, information about the European Reference Networks, lists of national Centres of Excellence, and advocate for the long-term sustainability of the European Reference Networks. ECPC will also offer administrative and technical support to the Working Group on Rare Cancers.

Timeframe

- January 2019: Educational tools and learning programmes for the rare cancer patient communities
- June 2019: Annual meeting of the Working Group on Rare Cancers during the European Cancer Patient Coalition Congress
- July 2019: Joint Action on Rare Cancers Steering Committee meeting (to be confirmed)

5 CAPACITY-BUILDING ACTIVITIES

5.1 Shared decision-making workshop (new, pending)

Board champion: Kathi Apostolidis, Matti Jarvinen

Staff responsible: Partnerships and Communications Manager

Shared decision making (SDM) is a process in which physicians and patients work together to select tests, treatments, management or support services, based on clinical evidence and the patient's informed preferences. It involves the provision of evidence-based information about options, outcomes and uncertainties, together with decision support counselling and a systematic approach to recording and implementing patient's preferences. SDM is appropriate for care where patients face major healthcare decisions where there is more than one feasible and evidence-based option, for decisions about screening tests and preventive strategies, and for choosing care and support services for long-term conditions.

This process is rarely practiced in European oncology, with the exception of a few medical centres in the UK, Netherlands, and France. Most European patients and their families have very little knowledge or understanding about shared decision-making. Moreover, some healthcare professionals may be reluctant to embrace shared decision-making, because they fear it will require more of their time, when in fact, one of the aims is to reduce the burden on the healthcare system. It is very important that people with cancer and health professionals make decisions together using shared decision making. ECPC will invite its Members to participate in a one-day workshop to bring together patients, patient advocates, and health professionals to discuss the importance of shared decision making. This will be accompanied by short, easy and practical information for ECPC Members. Speakers may include representatives from the European Organisation for Research and Treatment of Cancer (EORTC), the Informed Medical Decision Making Foundation, Maastricht University, Cardiff University, or Dartmouth University.

Deliverables

- Shared decision-making workshop and report

Timelines

- Month 0: Funding secured
- Month 1: Project kick-off
- Month 2: Agenda drafted
- Month 3: Agenda finalised, speakers invited
- Month 5: Participants invited
- Month 8: Shared decision-making workshop
- Month 9: Report on shared decision-making workshop

5.2 Annual Congress 2019 (ongoing, confirmed)

Board Champions: Francesco De Lorenzo, Kathi Apostolidis, Jana Pelouchova, Andrew Winterbottom, Matti Järvinen, Maude Andersson, Ken Mastris

Staff responsible: Partnerships and Communications Manager

The European Cancer Patient Coalition Annual Congress is Europe's largest gathering dedicated to people with cancer, hosting more than 120 cancer patients' organisations from over 20 European countries. Since 2013, the European Cancer Patient Coalition Annual Congress has increased its capacity and scope, with over 150 participants in 2016, 2017, and 2018.

The 2019 Annual Congress will be of particular importance for ECPC, since the new 2019-2021 Board will take up its mandate. This makes the 2019 Annual Congress an even more appealing event for all our stakeholders, as they will have the unique chance to meet the new Board during the meeting.

A Members survey will also be launched at the 2019 Annual Congress, in order to identify the priorities of European cancer patient organisations.

The Annual Congress is divided into two main parts:

- Friday: Welcome, overview of ECPC activities, networking dinner;
- Saturday events: ECPC puts together an engaging programme of lectures, roundtables and workshops to provide its Members with the latest and most important updates for people with cancer;

Representatives from the European Commission, the European Medicines Agency, the European Parliament and the Council regularly feature as speakers during the Assembly. Key opinion leaders from the world of cancer research never miss their chances to give their support to ECPC, presenting the results of their latest findings during the Annual Congress.

The annual meeting also represents a great chance for industry to better understand the status of cancer patients' advocacy in Europe and listen live to the voice of expert patients and patients' advocates.

Furthermore, several milestones from the 2019 Action Plan will occur during the Annual Congress, including:

1. Working Group for Rare Cancers meeting
2. Working Group for Urological Cancers meeting
3. Legal Network for Cancer Patients meeting

The European Cancer Patient Coalition Annual Congress will take place in June 2019, in Brussels, Belgium.

Evaluation

The success of this project will be measured by:

- Number of people and organisations attending the Annual Congress
- Proportion of positive responses from people who complete the Congress survey
- Traditional media engagement about the Annual Congress
- Social media engagement about the Annual Congress

5.3 Newsletter (ongoing, confirmed)

Board Champion: Andrew Winterbottom, Matti Jarvinen

Staff responsible: Partnerships and Communications Manager

Thanks to Mailchimp, ECPC can monitor and analyse what its Members find more interesting, which consolidates the Coalition's understanding of its Membership's needs. The Coalition has consolidated and nurtured a very successful newsletter system that reaches some of the most committed cancer patients' advocates in Europe and provides useful information.

In 2019, ECPC will continue to provide its Members and stakeholders with information on policy and advocacy in cancer at the EU level. The objective is to continue to raise ECPC's Members' understanding of the complex EU public health policy panorama. This will serve the double purpose of making ECPC's work and achievements in policy better understood, and, most importantly, raise ECPC's Members' awareness on the impact of EU health policies on their life and how they can proactively contribute to ECPC's policy work. This newsletter will also include relevant information on any new cancer treatments that have been authorised by the European Medicines Agency.

As ECPC also actively participates in several of the European Union's Research and Innovation framework programmes, such as IMI, Seventh Framework Programme and Horizon 2020. In 2018, ECPC established a Quarterly Projects Newsletter addressed to stakeholders and Members with updates of the latest in the various EU projects in which ECPC is partnering in, and will continue this activity in 2019.

Implementation

The European Cancer Patient Coalition Newsletter will cover news and information regarding ECPC's activities and projects.

Deliverables

- 12 issues of European Cancer Patient Coalition Newsletter

Timeframe

- January - December 2019: production of 12 ECPC Newsletters (once a month)

Evaluation

The success of this project will be measured by:

- How many emails were delivered
- How many people opened the email
- Percentage of people who clicked on a link
- Whether or not clicks were at the top or bottom of the email
- Whether or not clicks were on pictures or text
- How ECPC compares to other NGOs
- Engagement by country

6 HEALTH AND RESEARCH PROGRAMMES

6.1 European Reference Networks (ongoing, confirmed)

Board champion: Jana Pelouchova

Staff responsible: Head of Health and Research Programmes

European Reference Networks (ERNs) are virtual networks involving healthcare providers and other stakeholders across Europe. They aim to tackle complex or rare diseases and conditions that require highly specialised treatment and a concentration of knowledge and resources. European Reference Networks will reinforce their capacities to benefit thousands of Europeans diagnosed with rare or complex conditions from 2017 to 2021.

The Joint Action on Rare Cancers (Section 4.8) is developing guidelines to improve the efficacy and impact of the European Reference Networks that include rare cancers.

There are several European Reference Networks that include rare cancers:

European Reference Network on rare solid cancers (EURACAN)

The European Reference Network for rare solid cancers (EURACAN) gathers all rare adult solid cancers. More than 300 rare cancers have been identified, which are grouped in 10 domains corresponding to the RARECARE classification, in addition to the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10). EUROCAN is coordinated by the Centre Leon Bernard in collaboration with EURORDIS.

ECPC is one of the patient organisations representing the needs, rights and hopes of adults with rare solid cancers. ECPC is an elected European Patient Advocacy Group member (ePAG) and Co-Lead in the EURACAN Transversal task Force on Dissemination and Communication.

European Reference Network on endocrine conditions (Endo-ERN)

Rare endocrine conditions include too much, too little or inappropriate hormonal activity, hormone resistance, tumour growth in endocrine organs, or diseases with consequences for the endocrine system. Endo-ERN aims to deliver improved diagnostic trajectories, treatment, quality of care and measurable outcome for patients with rare endocrine conditions by facilitating multidisciplinary and cross-border collaboration and education and by listening to the patient.

European Reference Network on genetic tumour risk syndromes (ERN GENTURIS)

Genetic tumour risk syndromes are disorders in which inherited genetic mutations strongly predispose individuals to the development of tumours. ERN GENTURIS is working to improve identification of these syndromes, minimise variation in clinical outcomes, design and implement guide- lines, develop registries and biobanks, support research, and empower patients.

European Reference Network on paediatric cancer (ERN PaedCan)

Paediatric cancer is rare and comes in multiple subtypes. ERN PaedCan is working to improve access to high-quality healthcare for children with cancer whose conditions require specialist expertise and tools not widely available due to low case volumes and a lack of resources.

ERN on haematological diseases (EuroBloodNet)

Haematological diseases involve abnormalities of blood and bone marrow cells, lymphoid organs and coagulation factors, and almost all of them are rare. They can be subdivided into six categories: rare red blood cell defects; bone marrow failure; rare coagulation disorders; haemochromatosis and other rare genetic disorders of iron synthesis; myeloid malignancies; and lymphoid malignancies. EuroBloodNet will seek to improve access to healthcare for rare haematological diseases patients; to promote guidelines and best practice; to improve training and knowledge-sharing; to offer clinical advice where national expertise is scarce; and to increase the number of clinical trials in the field.

6.2 IMI: PREFER patient preferences (ongoing, confirmed)

Board champions: Francesco de Lorenzo, Kathi Apostolidis, Maude Andersson

Staff responsible: Head of Health and Research Programmes

The project PREFER, funded by the Innovative Medicines Initiative (IMI), will develop guidelines on when and how industry and regulatory agencies should use patient preferences in the development of medicinal products, throughout the development lifecycle, from pre-clinical to post-marketing.

strengthen patient-centric decision making throughout the life cycle of medicinal products (a term which, in the context of this proposal, also includes medical devices) by developing evidence-based recommendations to guide industry, Regulatory Authorities, Health Technology Assessment bodies, reimbursement agencies, academia, and health care professionals on how and when patient-preference studies should be performed, and the results used to support and inform decision making. It is a five-year project that is running from 2016 to 2020.

PREFER is divided into four 'work packages'. The methodology work package looks at the concerns stakeholders have around the use of patient-preference studies. Based on what they find, they will make recommendations about what methodologies to use in case studies that the case study work package will design and carry out. After evaluating the case studies, the recommendations work package will take over and draft recommendations based on the work. The management work package will provide oversight.

Within the project, the European Cancer Patient Coalition leads the Patient Advisory Group with the other patient organisations involved (Muscular Dystrophy UK, European Patients Forum and the International Alliance of Patient Organisations), is providing feedback on patient preference elicitation issues and approach, and is contributing to the drafting of recommendations, and is contributing to dissemination activities with an event at the end of the project.

Patient Advisory Group members are directly involved in activities within all work packages of PREFER, sharing common expectations and ensuring that the methodologies identified correspond to the patient views, experiences and preferences.

PREFER is funded through the IMI2 Joint Undertaking. IMI2 receives support from the European Union's Horizon 2020 research and innovation programme and the European Federation of Pharmaceutical Industries and Associations (EFPIA).

6.3 IMI: Big Data for Better Outcomes: DO-IT (ongoing, confirmed)

Board champion: Ken Mastris

Staff responsible: Head of Health and Research Programmes

The overall goal of the Big Data for Better Outcomes (BD4BO) programme is to facilitate the use of 'big data' to promote the development of value-based, outcomes-focused healthcare systems in Europe. Big data has become a common theme in global policy and clinical arenas. The growing focus on its use in health has come as policy makers and clinical leaders recognise the potential value in leveraging data to optimise the quality of care, improve patient outcomes, and increase efficiency in healthcare. The DO-IT project will run from 2018 to 2019.

Data for better Outcomes, policy Innovation and healthcare system Transformation (DO-IT) will:

- Define a programme strategy that ensures quality, consistency and sustainability of health outcomes related activities across individual BD4BO projects.
- Integrate, synthesise, and manage knowledge from all BD4BO projects, making it easily accessible via a single knowledge exchange platform.
- Act as pivotal point of collaboration, stakeholder engagement and communication for all BD4BO projects.
- Provide transparency and enable the use of patient health data and human biological samples for research purposes by developing minimum data privacy standards for Informed Consent Forms and supporting materials.

ECPC is involved in dissemination and communication (WP3) and in the development of the informed consent forms and the training materials (WP4). ECPC will collaborate with European expert patient groups in order to develop further the informed consent forms and their supporting materials. Patient organisations and other stakeholders will generate an iterative, consultative process to develop successive versions of minimum data privacy standards and structure recommendations for these informed consent forms. ECPC will participate in compiling concise and comprehensive documents which will provide European patients with the basic knowledge to understand the importance and power of clinical trials, bio banking, and exploratory research such as biomarkers. ECPC will also contribute to the successful dissemination of the project's deliverables.

DO-IT is funded through the IMI2 Joint Undertaking, and is part of the Big Data For Better Outcomes Programme (BD4BO). IMI2 receives support from the European Union's Horizon 2020 research and innovation programme and the European Federation of Pharmaceutical Industries and Associations (EFPIA).

6.4 IMI: Big Data for Better Outcomes: PIONEER prostate cancer (ongoing, confirmed)

Board champions: Ken Mastris, Maude Andersson

Staff responsible: Head of Health and Research Programmes


The overall goal of the Big Data for Better Outcomes (BD4BO) programme is to facilitate the use of 'big data' to promote the development of value-based, outcomes-focused healthcare systems in Europe. Big data has become a common theme in global policy and clinical arenas. The growing focus on its use in health has come as policy makers and clinical leaders recognise the potential value in leveraging data to optimise the quality of care, improve patient outcomes, and increase efficiency in healthcare. The PIONEER Project (Prostate Cancer DiagnOsis and TreatmeNt Enhancement through the Power of Big Data in EuRope) has 32 partners across 9 countries.

At present, there are a number of critical knowledge gaps that the project will address in relation to the screening, diagnosis and treatment of prostate cancer patients, including:

- lack of standardisation of prostate cancer definitions across all stages of the disease;
- insufficient knowledge of the risk factors for developing prostate cancer;
- insufficient knowledge of patient characteristics, including genetic profiles, for optimal stratification of patients at time of diagnosis;
- lack of meaningful engagement of all key stakeholders, including patients, when defining core disease outcome sets;
- lack of effective implementation of knowledge gained into clinical practice including knowledge informed by real world data.

This lack of knowledge means that suboptimal ability to predict which patients will have the best outcomes with specific treatments and which patients may be managed safely without treatment.

PIONEER's unique approach is to firstly identify critical evidence gaps in prostate cancer care through a detailed prioritisation exercise including all stakeholders, such as clinicians, patient organisations, researchers, industry, and payers. PIONEER will then standardise and integrate existing 'big data' from quality multidisciplinary data sources into a single innovative data platform, which will leverage two existing data platforms, tranSMART and OHDSI, from previous IMI projects. This will result in a unique and comprehensive data set that consists of the most relevant prostate cancer clinical trials and registries, large epidemiological cohorts, electronic health records, and real-world data from different European and non-European patient populations. Based on a unique set of methodologies and advanced analytical methods, PIONEER will transform the field of prostate cancer care with particular focus on improving prostate cancer-related outcomes, health system efficiency and the quality of health and social care. In addition, PIONEER will provide recommendations for standardised care pathways for clinical centres across Europe.



The use of these data sets during and beyond PIONEER will be based on the FAIR guiding principles, meaning they will be Findable, Accessible, Interoperable and Reusable (FAIR) both for human and machine-driven activities. This will increase their interoperability with current and future multifactorial prostate cancer datasets. Lastly, PIONEER will use 'big data' to test new prognostic algorithms to provide new hypotheses for future high quality prospective studies, and where appropriate, for implementation into daily clinical practice.

PIONEER will empower meaningful improvement in clinical practice, health outcomes and health-economic outcomes across Europe. It will achieve this by applying advanced data analytics and developing a data-driven platform of unparalleled scale, quality and diversity.

PIONEER is funded through the IMI2 Joint Undertaking, and is part of the Big Data For Better Outcomes Programme (BD4BO). IMI2 receives support from the European Union's Horizon 2020 research and innovation programme and the European Federation of Pharmaceutical Industries and Associations (EFPIA).

6.5 Innovative Training Network: ELBA liquid biopsies (ongoing, confirmed)

Board champions: Jana Pelouchova, Kathi Apostolidis, Francesco de Lorenzo


Staff responsible: Health and Research Officer

Innovative Training Networks are structured way of training PhD students in collaboration with academic and non-academic colleagues in other EU Member States and beyond. PhD students or researchers with less than four years of research experience can apply for the positions that are especially created by these networks on the EURAXESS job portal. The Innovative Training Networks train a new generation of creative, entrepreneurial, and innovative PhD students, who are able to face current and future challenges and to convert knowledge and ideas into products and services for economic and social benefit. The ELBA project is running from 2018 to 2021.

Liquid biopsies have been heralded as a game changer in cancer management, with blood tests offering a minimally invasive, safe, and sensitive alternative or complimentary approach for tissue biopsies. Blood represents a rich source of information through which solid cancers (and their subtypes) can be detected, identified and classified, and matched to a specific therapy. However, despite the potential of individual approaches, the promise of liquid biopsies has not yet materialised in the clinic. Widespread deployment requires creative next-generation researchers with an innovative mindset with access to a unique toolbox, including medical know-how, molecular diagnostics expertise (from health economics to regulatory), and statistical/bioinformatical proficiency.

Currently, there are no comprehensive training programmes to address this need. To move the promising liquid biopsy technology out of its infancy, the research programme and educational curriculum of the European Liquid Biopsy Academy (ELBA) will cover the entire value chain of diagnostics development and integrate all required disciplines and sectors.

The European Liquid Biopsy Academy (ELBA) is an Innovative Training Network that will award positions to 15 PhD students and researchers with less than four years of research experience. These early stage researchers will be taught the skills to circumvent the obstacles currently hampering effective development and commercialisation of liquid biopsy approaches. The PhD students will make scientific advances towards widespread implementation of blood-based diagnostics tests, create a sustainable network to foster long-term multidisciplinary relationships to accelerate clinical translation of blood-based diagnostics tests and publish a roadmap to liquid biopsy test development.



By creating a sustainable network to foster long-term multidisciplinary relationships and communication networks with various stakeholders we aim to accelerate clinical translation of these blood-based diagnostics. Most importantly, the partners have designed a well-balanced training programme to provide excellent career opportunities for the 15 ELBA PhD students. This includes training on state-of-the-art technologies and tools; bioinformatics, biostatistics and mathematical modelling; health economics and health technology assessment; diagnostic test development (including intellectual property and regulatory affairs); transferable skills (including leadership) and patient inclusion.

ECPC will contribute to the training courses by offering expertise in patient involvement, sitting in the Project Advisory Board, and using its communication channels to share information about the project. A representative of the European Cancer Patient Coalition will attend each annual meeting and deliver a presentation on the important role that people with cancer play in research. ECPC will also participate in workshops on communicating complex research results to a public audience, understanding the patient perspective, and on scientific writing.

ELBA is funded by Horizon 2020: the European Union Framework Programme for Research and Innovation

6.6 Innovative Training Network: PREDICT radiomics (ongoing, confirmed)

Board Champion: Maude Andersson, Francesco de Lorenzo


Staff responsible: Health and Research Officer

Innovative Training Networks are structured way of training PhD students in collaboration with academic and non-academic colleagues in other EU Member States and beyond. PhD students or researchers with less than four years of research experience can apply for the positions that are especially created by these networks on the EURAXESS job portal. The Innovative Training Networks train a new generation of creative, entrepreneurial, and innovative PhD students, who are able to face current and future challenges and to convert knowledge and ideas into products and services for economic and social benefit. The PREDICT project is running from 2018 to 2021.

PREDICT is a project coordinated by the Maastricht University that will train 15 PhD students to become leaders in the field of radiomics and personalised medicine, ultimately aimed at improving the diagnosis and treatment of cancer.

The high degree of tumour (genomic and phenotypic) heterogeneity can influence the patient's response to therapy, and can hamper the wide deployment of personalised medicine for cancer treatment. Thus, there is an imperative need for new technologies that can accurately detect tumour heterogeneity, allow for patient stratification, and assist clinicians in providing the right diagnosis and treatment for the right patient. PREDICT's mission is to address this unmet need.

Radiomics, a newly emerging field that uses high-throughput extraction of large amounts of features from radiographic images, can boost the field of personalised medicine. The analysis of medical images taken as standard-of-care allows radiomics to capture tumour heterogeneity and to generate 'tumour-specific' signatures in a non-invasive way, without the need of assessing the patient's genetic profile. Thus, radiomics, if linked to big-data and decision support systems, can be used as a diagnostic tool for patient stratification, for prediction of treatment response and for guidance, involving the patient, of clinical decisions in oncology. However, researchers that understand cancer biology, advanced imaging and big data analytics are virtually absent. Even more challenging is to translate the outcomes into actual clinical tools involving the patient.



PREDICT will train 15 highly promising PhD students in the emerging field of radiomics and big data. These early-stage researchers will be trained to implement the automatic exploitation of large amounts of imaging data to drive decision-making algorithms that will guide diagnosis and treatment of different types of cancer and to develop 'tumour-specific' signatures integrated in multifactorial DSS. They will become experts and innovators in radiomics, big data and decision support systems, which will allow them to bring unique solutions towards the clinic. PREDICT builds upon a strong consortium with 8 academic and 10 non-academic partners that are all pioneers in their respective fields.

ECPC will take part in the Marie Curie Innovative Training Network 'PREDICT'. The Coalition will contribute to the training courses by offering its expertise in patient involvement as well as advocating the role of patients/co-researchers as the best partnership model between researchers and patients.

PREDICT is funded by Horizon 2020: the European Union Framework Programme for Research and Innovation

6.7 H2020: LEGACy gastric cancer (new, confirmed)

Board champions: Ken Mastris, Maude Andersson

Staff responsible: Head of Health and Research Programmes

Gastric cancer is the third leading cause of cancer death in both sexes, and high mortality rates are present in Central and Eastern Europe, and in Central and South America. The “Latin American and European countries network for precision medicine approach in Gastric Cancer” (LEGACy) project aims to tailor cancer control to specific patient groups by establishing evidence obtained through international high-quality translational collaborative research. LEGACy aims to design a cost-effective diagnosis algorithm based on the tumour biology knowledge due to identify the high-risk groups in patients diagnosed with stage III and IV gastric cancer and compare the regional differences between Community of Latin American and Caribbean States (CELAC) and EU countries participating in this project. The project will run from 2019 to 2022.

ECPC will lead the Work Package on 'Communication and Dissemination', which is responsible for a full dissemination, exploitation and communication of all project outreach activities, empowering patients and their families by ensuring new insights are effectively communicated and a Stakeholder final event at the completion of the project. ECPC is also part of the Work Package on 'Coordination and Management', responsible for the ethical oversight of the project and ensuring patient-centricity. Additionally, ECPC will be contributing to Work Package 3 through the designing of a project website with access to the different data collected for the facilitation of communication between various stakeholders, as well as Work Package 4 by providing the patient perspective for the translation to clinical practice.

LEGACy is funded by Horizon 2020: the European Union Framework Programme for Research and Innovation.

6.8 H2020: DIAdIC psychosocial interventions (new, confirmed)

Board champions: Maude Andersson, Ken Mastris

Staff responsible: Health and Research Manager

Dyadic Psychosocial Interventions for people with Advanced cancer and their Informal Caregivers (DIAdIC) is a transdisciplinary, cross-national research project evaluating the effectiveness and cost-effectiveness of 2 psychosocial and educational interventions, aiming to inform European countries on which interventions generate the most favourable outcomes. The project will run from 2019 to 2023.

ECPC will lead the Work Package on 'Dissemination and Communication', which is responsible for a full dissemination, exploitation and communication of all project outreach activities. It is also responsible for empowering patients and their families by ensuring new insights are effectively communicated. ECPC will draft press releases, and contribute to the position paper that is to be developed by the project with policy and awareness recommendations. ECPC will organise a virtual conference for patients, family caregivers and the general public, as well as a stakeholder final event at the completion of the project. ECPC will also be contributing to Work Package 9 by organising reflection groups to increase stakeholder involvement working together Work Package 4 in writing implementation guidelines for the DIAdIC interventions.

DIAdIC is funded by Horizon 2020: the European Union Framework Programme for Research and Innovation.

6.9 H2020: IMMUNISA cervical cancer (ongoing, confirmed)

Board champions: Maude Andersson, Kathi Apostolidis

Staff responsible: Health and Research Manager

Cervical cancer can be caused by the human papillomavirus. Once infected, prophylactic vaccines no longer prevent the development of premalignant lesions and cervical cancer, which can only be treated with surgery, chemotherapy or radiotherapy. Targeted immunotherapy could be an effective approach to induce a tumour-directed immune response. This response can be induced with a therapeutic vaccine that mediates expression of immunogenic antigens by dendritic cells, which in turn cause a strong T-cell mediated immune response directed towards tumour cells. IMMUNISA proposes to use a therapeutic vaccine, to mediate dendritic-cell antigen expression, resulting in robust T-cell responses against the proteins expressed on the cervical cancer tumour cells. In a multi-centre, randomised Phase 2 clinical trial called CervISA-2, IMMUNISA will investigate if a therapeutic cancer vaccine in combination with chemotherapy can prolong the progression free survival and overall survival of people with recurrent or metastatic cervical cancer. This project will run from 2017 to 2023.

ECPC ensures the project's compliance with the needs of the people with cancer and is involved in the work package responsible for project management and dissemination. ECPC is involved in Work Package 6: Project Management & Dissemination. The European Cancer Patient Coalition reviews the dissemination strategy, promote the project on its website and in its newsletter, disseminate brochures and newsletters, and participate in the IMMUNISA meetings and conferences.

IMMUNISA is funded by Horizon 2020: the European Union Framework Programme for Research and Innovation.

6.10 H2020: ImmunoSABR metastatic lung cancer (ongoing, confirmed)

Board champion: Ken Mastris, Francesco de Lorenzo

Staff responsible: Health and Research Manager

ImmunoSABR is geared towards opening up a new paradigm in treating metastatic cancer by obtaining clinical proof of concept for a novel bi-modal curative treatment strategy. High precision stereotactic ablative radiotherapy (SABR) is combined with immunotherapy to form a powerful synergistic anti-tumour strategy. ImmunoSABR will run from 2017 to 2022.

The ImmunoSABR clinical trial is trying to find a better way to treat metastatic cancer. In this randomised open label phase II clinical trial, stereotactic ablative radiotherapy (SABR) will be combined with L19-IL2 immuno-oncology therapy in people with limited metastatic non-small cell lung cancer. ImmunoSABR will also use cancer biomarkers to develop a way to predict which people will most benefit from this novel treatment strategy.

ECPC will give input into the development of the informed consent forms and the patient information brochure. In addition, ECPC will convey information about the ImmunoSABR trial to its own network, all other relevant European patient organisations, and the general public. Finally, ECPC will organise a dissemination activity within the European Parliament at the conclusion of the project.

This project received funding from the European Union's Horizon 2020 research and innovation programme

6.11 H2020: MM04 / DENIM mesothelioma (ongoing, confirmed)

Board champion: Kathi Apostolidis, Francesco de Lorenzo

Staff responsible: Head of Health and Research Programmes

Malignant pleural mesothelioma is a rare but highly aggressive cancer that annually kills about 43,000 people worldwide. It is mainly caused by asbestos inhalation due to asbestos exposure and, although asbestos use is decreasing, mesothelioma incidence is expected to keep increasing for the next 20-50 years due to its long latency period. Unfortunately, there is no curative therapy for mesothelioma, making it a highly fatal disease. There is thus a clear unmet medical need for the treatment of mesothelioma. The main objective of the project is to demonstrate the efficacy of dendritic cell-based immunotherapy in a randomised Phase 2/3 clinical trial in order to address this urgent need. The project will run from 2016 to 2019.

ECPC is involved in Work Package 6, the Work Package responsible for the effective dissemination of the results to external stakeholders. ECPC disseminates the project news and results to all its Member patient organisations via ECPC newsletter as well as via ECPC website and social media channels. Furthermore, having ECPC as a partner will ensure that the developments of the project are designed and adapted to respond better to the needs of the patients.

This project received funding from the European Union's Horizon 2020 research and innovation programme, grant agreement No. 668769

6.12 H2020: Transcan-2 European Research Area (ongoing, confirmed)

Board champions: Francesco de Lorenzo, Kathi Apostolidis, Ken Mastris

Staff responsible: Head of Health and Research Programmes

The ERA-NET: Aligning national/regional translational cancer research programmes and activities - TRANSCAN-2 is a five-year project funded by the European Commission under the EU framework programme Horizon2020 that will run from 2015 to 2019.

The objective of TRANSCAN-2 is to contribute to the building of the European Research Area through the coordination of activities of national and regional translational cancer research funding organisations, aiming at the integration of basic, clinical and epidemiological cancer research and facilitation of transnational cancer funding in Europe with the ultimate aim to streamline EU-wide cancer screening, early diagnosis, prognosis, treatment and care.

TRANSCAN-2 has the goal of coordinating national and regional funding programmes for research in the area of translational cancer research. The specific challenge is to promote a transnational collaborative approach between scientific teams in demanding areas of translational cancer research while avoiding the duplication of efforts and ensuring a more efficient use of available resources, to produce significant results of higher quality and impact, and share data and infrastructures.

The Italian Ministry of Health and the National Institute of Health act as Joint Call Secretariat. ECPC is represented in the Scientific Advisory Board, one of the three main governing bodies of the network. The Scientific Advisory Board serves as a source of input on and feedback about the work of TRANSCAN and is in close collaboration with the other two bodies: The Network Steering Committee, as the strategic decision-making body and the Network Coordination Unit, as the body responsible for the day-to-day management and the external TRANSCAN consortium representation.

This project received funding from the European Union's Horizon 2020 research and innovation programme

6.13 FP7: eSMART mHealth symptom management (ongoing, confirmed)

Board champion: Kathi Apostolidis

Staff responsible: Head of Health and Research Programmes

eSMART (e-Symptom Management using Advanced Symptom Management System Remote Technology) is a research project financed under the Seventh Framework Programme, coordinated by the University of Surrey. The clinical trial aims to evaluate the impact of a mobile phone-based, remote monitoring, symptom management intervention (the Advanced Symptom Management System, ASyMS) on the delivery of care to people diagnosed with non-metastatic breast, colorectal or haematological cancer during chemotherapy and for one year after the end of treatment. eSMART involves 10 world-renowned European and one American partner, among them seven universities, university medical centres and a technology company. The project will run from 2014 to 2019.

eSMART aims to demonstrate how technology can be instrumental in the delivery of patient focused, anticipatory care that improves the outcomes and quality of life of people with cancer. It will demonstrate the effects of a real-time, mobile phone based, remote patient monitoring and care. The interventions will address key cancer patient symptoms and cancer care results and the delivery of care during and after chemotherapy. The remote patient monitoring system via mobile phone, i.e., the Advanced Symptom Management System (ASyMS), will help people with cancer reduce the symptom burden experienced during chemotherapy and improve their quality of life during acute treatment and survivorship. Most important, the project results will facilitate changes in clinical practice thus, leading to improved delivery of cancer care.

Patients have a prominent co-researcher role in eSMART and participate in all project activities from project concept to implementation. ECPC, in its patient representative role participates equally with other researchers in the eSMART project in the Project Technical Management Board, in the Publications Committee, and in the Exploitation Committee, offering advice and feedback to ensure that the trial is designed and conducted in line with patients' needs and preferences.

In 2019, ECPC will co-lead the final eSMART event in Brussels.

This project received funding from the European Union's Horizon FP7 research and innovation programme

