
European Cancer Patient Coalition Action Plan 2018

Empowering Europeans affected by cancer



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1 Why work with ECPC?

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.

2 ECPC policy achievements in 2017

2.1 WHO Cancer Resolution

In May 2017, the 70th World Health Assembly approved the resolution on 'Cancer prevention and control in the context of an integrated approach', and noted the WHO report on cancer prevention and control.

This resolution marked the first resolution dedicated to cancer by the WHO in over a decade, and provides a set of recommendations to control and prevent cancer. It complements the WHO's Global Action Plan for the Prevention and Control of Non-Communicable Diseases 2013-2020. The WHO 2017 Cancer Resolution represents a firm commitment of all countries to keep cancer control as a world health priority.

During the negotiations of the new resolution, the European Cancer Patient Coalition has been making great efforts to improve the text by recognizing the importance of patients' organisations in the design and provision of services for the prevention, control, treatment and care of cancer. ECPC's President, Francesco De Lorenzo, advocated for the inclusion of the role of patient organisations in the resolution, and sent this recommendation to Margaret Chan, outgoing WHO Director-General, and to Heidi Botero-Hernandez, First Secretary of the Permanent Mission of Colombia to the UN in Geneva and Chair of the informal consultations for the cancer resolution. Thanks to these efforts, the following clause was added to the resolution:

“
The Seventieth World Health Assembly, [...]

URGES Member States [...],

(19) to continue fostering partnerships between government and civil society, building on the contribution of health-related nongovernmental organizations and patient organizations, to support, as appropriate, the provision of services for the prevention and control, treatment and care of cancer, including palliative care;

2.2 Joint Action on Cancer Control

In February 2017, the new *European Guide on Quality Improvement in Comprehensive Cancer Control* was presented during the final conference of the Joint Action on Cancer Control (CanCon) in Malta. The Joint Action on Cancer Control was a common effort between representatives from 17 EU Member States, co-funded by the European Commission's Directorate-General for Health and Food Safety. The European Cancer Patient Coalition was involved in the Joint Action on Cancer Control since the beginning, providing insight and steering the debate related to several chapters of the Guide. Many of the in the final Guide and policy papers come directly from the people fighting against cancer every day.

The European Guide on Quality Improvement in Comprehensive Cancer Control presents key recommendations to potentiate EU countries' capacity to fight cancer. The recommendations span the whole patient journey from prevention to treatment and survivorship. The Guide explains in detail which

measures EU governments should implement to make National Cancer Control Plans more resilient and effective, focusing on key aspects of cancer care: integrated cancer control, disinvestment, community-level cancer control, survivorship and rehabilitation, and screening.

ECPC remains committed to the development of EU initiatives on cancer control. For this reason, ECPC is engaging with former CanCon partners and EU health ministries to define the content and patients' role of the next Joint Action on cancer control, foreseen in the 3rd Health Programme's Work Programme for 2017.

2.3 Joint Action on Rare Cancer *(refer to page 35 for further details and 2018 Activities)*

The European Commission's Joint Action on Rare Cancers is aimed at prioritising rare cancers within the national and European agenda, and improving the European Reference Networks' ability to tackle rare cancers. The Joint Action on Rare Cancers will achieve these aims through a series of work packages that include those addressing epidemiology, quality of care, research, childhood cancers, and rare cancer policy. The final goal of the Joint Action on Rare Cancers will be to contribute to improve health outcomes for patients with rare cancers and to decrease health inequalities for rare cancer patients across Europe.

The Joint Action on Rare Cancers is coordinated by the Italian Fondazione IRCCS Istituto Nazionale dei Tumori. There are 34 partners involved in the Joint Action on Rare Cancers including 8 Ministries of Health/Cancer Control Programmes representatives (Cyprus, Czech Republic, France, Ireland, Italy, Malta, Poland, and Spain) and 26 universities, public health institutions, cancer registries, oncological institutes, patients' associations (ECPC, EURORDIS) and other societies/organisations (including the Organisation of European Cancer Institutes – OECI, and the European Society for Paediatric Oncology - SIOPE).

The European Cancer Patient Coalition 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

Website: <http://www.ecpc.org/activities/working-groups/177-wgrc>

The European Cancer Patient Coalition is involved in all the work packages of the Joint Action on Rare Cancers, which will run from 2016 to 2019. In order to better represent patients within the Joint Action on Rare Cancers, the European Cancer Patient Coalition has set up a Working Group on Rare Cancers where members can share their knowledge and cooperatively generate expertise. **ECPC will build on experience gained during its 3 years collaboration in the RARECAREnet project.**

2.3.1 Timelines

- 27 September 2017: Regional Conference on Rare Cancers, Milan
- 2-4 December 2017: 2nd ESO-ESMO-RCE Clinical Update on Rare Adult Solid Cancers, Milan
- 2-4 December 2017: ESO-ESMO-RCE Training Course for Rare Cancer Patient Advocates, Milan

2.4 EU Options to improve Access to Medicines

In March 2017, the European Parliament passed a new report on the options for improving access to medicines. It made several calls for action aimed at different institutions, both at EU and national levels, to address the most urgent problems in the issue of access to medicines.

ECPC was following this report closely since it was proposed in early 2016, and published a detailed position paper to ensure that the position of more than 400 cancer patients' organisation would be duly represented. ECPC welcomes the final report, as it contains most of the amendments proposed in ECPC's position paper.

The report focuses on several of the most crucial issues for patients, such as the transparency and collaboration on pricing and reimbursement of medicines, including the review of the Transparency Directive; the harmonisation of the health technology assessment at the European level; the regulation of parallel trade to avoid shortages of medicines in some countries; and the need for a patient-centric approach and a systematic involvement of patients in all decision-making schemes.

2.5 HTA Network

The European Commission's HTA Network is a network of national authorities – including all Member States and observer non-Member States – with the aim of supporting cooperation between them in terms of health technology assessment, and enable their responsible agencies for the exchange of information in order to avoid duplication of assessments and improve the timely outcomes of health technology assessments across Europe. The HTA Network is supported by the advice from the scientific and technical cooperation of EUnetHTA Joint Actions.

In late 2016, the HTA Network launched a call of expression of interest to establish the Stakeholder Pool. The Stakeholder Pool contributes to the policy development related to HTA at EU level through the HTA Network, making sure that their views are properly reflected. This Stakeholder Pool comprises representatives of patients and consumers, health providers, payers and industry.

In 2017, ECPC was accepted to form part of the new HTA Network Stakeholder Pool, representing cancer patients, alongside eight other organizations of patients and consumers. The collaboration with other organizations is very productive, as all parties involved have shown a high degree of engagement and willingness to collaborate.

ECPC continues to work on issues derived from its involvement in HTA Network, and is in close touch with the European Commission to ensure that the cancer patients' view is included in their work and ultimate proposal to regulate health technology assessments.

3 ECPC objectives for 2018

In June 2016, the ECPC General Assembly elected a new Board of Directors to lead the organisation until June 2019. Continuity is ensured by the permanence of 3 senior Members with previous experience, out of the total 7-person board. Furthermore, an Audit Committee and Scientific Committee have been established to ensure the sound financial management and scientific integrity of ECPC in 2018 and beyond. In 2017, the ECPC three-year strategy was presented to the General Assembly.

The main objective of the 2018 Action Plan is to confirm ECPC's leadership as the main voice of people with cancer in Europe, by strengthening the organisation and reinvigorating the connection between ECPC and its Membership. The advocacy and campaigning work for 2018 will continue following the main commitments taken in 2017.

Capacity-building initiatives

The European Cancer Patient Coalition 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. Between 2013 and 2016 the ECPC Membership increased by about 20%, passing the threshold of 400 Members across Europe. 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.

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 2018, ECPC will focus on developing the main policy themes:

- inequalities in access to quality cancer care;
- survivorship and rehabilitation issues;
- health technology assessment;
- participation of people with cancer in decision making;
- patient-centred research;
- support for rare cancers.

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 2018 is to confirm ECPC's commitments undertaken in 2017 and to keep following the main EU policy files for 2018.

Developing and consolidating partnerships

Between 2013 and 2016, ECPC consolidated the relationship with several other non-government organisations, and built new bridges with new non-government organisations. Among others, the results from the Memorandum of Understanding ECPC signed with ESMO, OEI, EORTC, and CDDF will ripen in 2018, contributing to a compelling pack of joint initiatives.

The objective for 2018 is to further enlarge partnerships with the existing non-government organisations, and to identify new stakeholders with which to establish similar formal partnerships.

Research

Research projects allow the European Cancer Patient Coalition to be on the forefront of scientific developments. The European Cancer Patient Coalition works to ensure that the patient perspective is heard and respected, while improving scientific knowledge about cancer. In 2018, ECPC will continue to

contribute to European research projects, as well as joining consortia to bid on future projects to begin in 2019.

The European Cancer Patient Coalition is actively involved in the design and implementation of EU funded research projects, among other ongoing activities. The European Cancer Patient Coalition participates in several of the European Union's Research and Innovation framework programmes: this includes IMI 1 projects, the Seventh Framework Programme (FP7), and IMI 2 projects under the current Horizon 2020 (H2020). 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.

Governance

Good governance is vital to ensure that the European Cancer Patient Coalition does good work. Governance is important 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. In 2018, ECPC will review its Statute and Regulations to ensure that they are compliant, up to date, and relevant.

Strengthening ECPC

Increase dissemination capacity

Between 2013 and 2016 ECPC has re-established itself as the voice of people with cancer in Europe. Our outreach has increased exponentially since 2013, with the establishment of a new Board, the hiring of a Community and Communications Manager, and the development of media partnership with some of Brussels' best news agencies.

On the basis of this solid background, ECPC will develop a new, comprehensive communication strategy. The objective is to provide better and more reliable dissemination potential to all ECPC initiatives, therefore:

- maximising ECPC's impact to internal and external stakeholder;
- increasing ECPC's donors' and partners' visibility;
- attracting new partners.

The new communication strategy will be implemented on 2 levels:

- Increasing ECPC's internal capacity to produce compelling contents;
- Establishing new partnership with professional media partners.

Increase ECPC fundraising capacity

From 2013 to 2016, the total funds raised by ECPC grew from less than 200,000 EUR to more than 600,000 EUR. This 300% increase in just 3 years is due to the reinforced trust of ECPC's industry partners and the European Commission in the capacity of ECPC to truly represent the voice of Europeans diagnosed with cancer.

To sustain ECPC's growth and the rise of responsibility, ECPC needs to differentiate ECPC's funding sources and increase the number of donors. To successfully accomplish these tasks, ECPC will:

- Seek the services of a reliable and professional fundraising agency;

-
- Build in-house capacity by training ECPC staff and hiring dedicated professionals.

4 How to read the ECPC Action Plan 2018

ECPC action plan outlines the main proposed activities for 2018. 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.
- **Advocacy and Policy 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;
- **Collaborations** are projects and initiatives implemented in partnership with ECPC's key stakeholders. They pertain to ECPC's capacity to represent people with cancer and aim at providing solutions and tools for patients, medical professionals and policymakers to key issues;
- **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;
- **European Union projects** allow ECPC to be on the forefront of scientific developments on cancer, providing the patients perspective to the best European Union research.

We enjoy the direct, experienced and voluntary support of ECPC's Board members and membership in the development and implementation of all activities of the Action Plan.

All ECPC's activities are clustered in chapters. For each activity or cluster of activities, ECPC prepared an accurate budget following the principle of full cost recovery.

Calendar of main activities for 2018

- **February**
 - World Cancer Day
- **March**
 - Nutrition awareness campaign
 - Patient Advocacy Session at European Association of Urology congress
 - ECPC-EORTC seminar on clinical trials
- **May**
 - Bladder cancer awareness campaign
- **June**
 - European Cancer Patient Coalition Annual Congress
 - Cancer Survivors Day
- **September**
 - European Society of Medical Oncology congress
 - Make sense of head & neck cancer awareness campaign
- **October**
 - World Cancer Congress
 - Personalised medicine month campaign
- **November**
 - Pancreatic cancer event in the European Parliament

Detailed monthly work plan of confirmed activities

January

Biosimilars white paper: identification of authors and reviewers
ECPC-EORTC clinical trial seminar: survey
Update of ECPC Website: About Us, Activities, Edu
Ongoing EU Projects
ECPC Monthly Newsletter

February

World Cancer Day: awareness campaign
Bladder cancer: release bladder cancer awareness campaign toolkit
Working Group on Rare Cancers: Videoconference
Ongoing EU Projects
ECPC Monthly Newsletter

March

Bladder cancer: Patient Advocacy Session at European Association of Urology congress
ECPC-EORTC clinical trials seminar
Biosimilars white paper: Table of contents
Bladder cancer: Urology cancer patient advocacy session at EAU Copenhagen
Ongoing EU Projects
ECPC Monthly Newsletter

April

Ongoing EU Projects
ECPC Quarterly Projects Newsletter

May

Biosimilars white paper: Review by ECPC members
Bladder cancer: Bladder Cancer Awareness Month
Ongoing EU Projects
ECPC Monthly Newsletter

June

European Cancer Patient Coalition Annual Congress
Cancer Survivors Day
Working Group on Rare Cancers: face-to-face meeting
Legal Network for Cancer Patients: face-to-face meeting
Ongoing EU Projects
ECPC Monthly Newsletter

July

Biosimilars white paper: review by ECPC members
Ongoing EU Projects

August

Ongoing EU Projects
ECPC Quarterly Projects Newsletter

September

Biosimilars white paper: final draft
Ongoing EU Projects
ECPC Monthly Newsletter

October

World Cancer Congress
European Society of Medical Oncology congress
Working Group on Rare Cancers: videoconference
IMI DO-IT BD4BO General Assembly
Joint Action on Rare Cancers General Assembly
ECPC Monthly Newsletter

November

Pancreatic cancer: event in the European Parliament
Bladder cancer: launch of updated policy and education webpages
IMI PREFER General Assembly
ECPC Monthly Newsletter

December

Biosimilars white paper: launch
Pancreatic cancer: produce report of November activities
Ongoing EU Projects
ECPC Monthly Newsletter

6 Education

6.1 Online educational HTA cancer module (new, confirmed)

Board champion: Dan Cimpoeru

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.

In 2018, ECPC will launch a new interactive online educational module focusing on health technology assessment of cancer treatments. This tool will aim to educate and empower cancer patient organisations to participate in their local health technology assessment of cancer treatments.

It will include:

- What is health technology assessment?
- Why cancer treatments are different from treatments for other types of diseases
- Defining survival, quality of life, and safety in people with cancer
- Short-term versus long-term cancer treatments
- Why some countries reimburse a cancer treatment and others don't
- How cancer patient organisations can be involved in the health technology assessment process

6.1.1 Implementation

ECPC will work with oncology and patient education experts, as well as Flywheel communications, to develop a new interactive online educational module focusing the health technology assessment of cancer treatments.

6.1.2 Deliverables

- New interactive online educational module on health technology assessment of cancer treatments
- Online awareness campaign promoting module

6.1.3 Timeframe

- Month 0: Funding confirmed
- Month 1: Project kick-off
- Month 2: Drafting of text
- Month 3: Expert review of text

-
- Month 4: First draft of interactive module
 - Month 5: Second draft of interactive module
 - Month 6: Final draft of interactive module
 - Month 7: Interactive module approved
 - Month 9: Interactive module integrated into ECPC website
 - Month 11: Launch of new interactive module

6.2 European policy webinar series (new, pending)

Board champion: Natacha Bolanos

The voice of ECPC is as strong as the participation of its Members to the life of the association. To make sure that the full potential of ECPC's policy stance is developed, we need to make sure that:

- All our Members can keep contributing to the development of our policy positions with the best information possible, while at the same time
- All our Members can strengthen their voice at the national level by using ECPC work in the best possible way

For this reason, ECPC will organise three one-hour webinars on EU policymaking. Three webinar series will be produced, with one series tailored to the South-East European Region, one region tailored to the Central & Northern European Region, and one region tailored to the Western European Region.

The webinars will be focused on how ECPC is shaping EU health policy and how ECPC Members can help ECPC at the national level to leverage on common points of interest. Many new ECPC Members are young associations, with strong links and experience at the national/local level, but with only basic understanding of the value of EU policies and their impact at the national level.

6.2.1 Implementation

6.2.1.1 Faculty

To ensure that the material and the content of the webinars are updated and reflect the real needs of cancer patients, ECPC will establish a group of experts from the ECPC Membership, responsible to oversee, input to and approve the material and programme of the webinar series.

6.2.1.2 Preparatory material

Before attending the webinars, participants will be provided access to an online platform where they can review preparatory material put together by ECPC. The main objective of the online platform is to provide the ECPC Members with key background information before accessing the webinars, so that the webinars will be a true moment of exchange and learning. The platform will also help the participants to reach the same understanding and use the same vocabulary, further facilitating the discussion and interaction during the face-to-face meetings.

The material will be produced by ECPC building on successful ad-hoc products that ECPC prepared in 2016 for its Members (Brain Tumour Charity and Lung Cancer Europe). On the base of these two success stories, the Secretariat will create a general briefing for the participants, including key background information such as:

- Understanding the European Union

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- Competences of the European Union in health
 - EU legislative process
 - The EU institutions and their work on health and cancer
 - EU initiatives on cancer
 - Basic notions on market authorisation of medicines
 - EU legislations affecting cancer patients
 - EU projects and activates on cancer
 - Joint Action on Cancer Control
 - Joint Action on Health Technology Assessment
 - Joint Action on Rare Cancers
 - Expert Group on Cancer Control

6.2.1.3 Webinars

ECPC will offer three one-hour webinars. The general structure of the three webinars will be:

1. Defining Priorities. Discussion on the main needs for the region
2. Mapping stakeholders. The key actors influencing the issues affecting the region
3. Planning actions. How to target decision makers in the region

ECPC will also seek additional resources for translations into languages other than English.

6.2.1.4 Final report

Following the webinar series exercise, a comprehensive report will be produced by the ECPC Secretariat to underline the feedback received from the Members. For this reason, a survey on the quality of the initiative will be disseminated to the participants after each webinar.

6.2.2 Deliverables

- An online platform to:
 - Connect all the participants to the webinars and provide them a place to discuss;
 - Disseminate preparatory material for the webinars;
- Preparatory material for the webinars, in the form of comprehensive briefings;
- Three one-hour webinars tailored to the three EU regions:
 - South-East European Region;
 - Central & Northern European Region;
 - Western European Region;
- Hand-outs for the webinars, specific to each Region;
- A final report with lessons learned and suggestion for future webinars.

6.2.3 Timeframe

- Month 0: Funding confirmed
- Month 1: Establishment of the group of experts, responsible of approving the webinar series programme and material;
- Month 2: definition of the Webinar series programme and production of the material for the webpage;
- Month 4: creation of the webpage;

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- Month 5: Launch of the call for expression of interest to all ECPC Members to take part to the webinar series;
 - Month 7: production of the website material;
 - Month 8: website operative;
 - Month 9: first webinar series for Central & Northern European Region;
 - Month 10: second webinar series for Western European Region;
 - Month 11: third webinar series for Eastern and Southern European Region;
 - Month 12: reporting and evaluation

6.3 Biobanking portal (new, pending)

Board champion: Dan Cimpoeru

Societal value of biobanking in oncology is beyond discussion. Cancer research would be substantially halted if biobanking was not in place, and, conversely, biobanks would not exist without the patients' donations.

ECPC and the BBMRI-ERIC (the Pan-European infrastructure of biobanks and biomolecular resources) fought together for a new General Data Protection Regulation, to ensure that historic and prospective research will be possible in Europe in the years to come. Now that this public health policy emergency has been resolved, ECPC and BBMRI-ERIC have decided to make sure that all Europeans with cancer can profit of the advantages benefits of contributing to European biobanks.

Do European patients know about the role of biobanks? What can patients benefit from once they donate samples and data to biobanks? In 2018, ECPC and BBMRI-ERIC will work together to provide an answer to these burning questions.

6.3.1 Implementation

ECPC and BBMRI-ERIC identified three key areas of intervention:

- **Patient education and awareness:** European patients do not know enough about the role of biobanks and the important contribution they make within cancer research, diagnosis and treatment. ECPC and BBMRI-ERIC will launch an awareness-raising campaign targeting patients;
- **Building national partnerships:** ECPC and BBMRI-ERIC are great examples of Pan-European collaborations, but it is crucial to create and nurture personal and professional relationships also at the national level. ECPC and BBMRI-ERIC will organise three national training, involving local patients' organisations and biobanks, to build trust and understanding among national players;
- **A European biobanking informed consent:** the new GDPR will harmonise national legislations on data protection, but several aspects will still be left to the different countries' interpretations. The new European policy challenge for ECPC and BBMRI-ERIC is to avoid the creation of 28 (or more) different biobanking informed consent, therefore fragmenting the way samples are collected at the national level.

To develop initiatives in these three areas, ECPC and BBMRI-ERIC will:

- Establish a dedicated working group, including BBMRI-ERIC node's experts and ECPC expert Members. The working group will be responsible to develop the specific initiatives and to identify those BBMRI-ERIC and ECPC Members best suited to implement the project;
- Nurture the collaboration between the ECPC Board and the BBMRI-ERIC Stakeholders Forum, in order to ensure consistency with the activities of the two organisations.

6.3.1.1.1 Portal

The portal will present patients with key and simple information on biobanking, underlining the advantages and the possible risks related to biobanking, to facilitate and increase a conscious participation of patients into biobanking.

The portal will be composed of:

- A homepage, with all the key content underlined and a comprehensive and understandable menu
- A section on the basics of biobanks, which would answer to the questions:
 - What is biobanking?
 - Why is biobanking important?
- A section focusing on the role of patients in biobanking, including information on:
 - Why should patients donate samples to biobanks;
 - What are the risks related to biobanking – patients' rights and data protection
 - A list of biobanks in Europe
- A section on the future of biobanking, stressing the increasing importance biobanks will have in the diagnosis and treatment of cancer. The session will therefore introduce the topics of:
 - Biobanking and personalised medicine
 - Genetic mapping
 - New diagnostics methods (liquid biopsy)
- A glossary, including the updated version of the existing ECPC Biobanks F.A.Q.

The content of the website will be produced by the ECPC-BBMRI-ERIC working group, in collaboration with a medical writer such as Health Policy Partnerships.

6.3.2 Deliverables

- An ECPC – BBMRI-ERIC Working Group, composed of patients, patients' advocates, biobanking experts, responsible for the implementation of all the initiatives of the ECPC-BBMRI-ERIC partnership;
- An online portal providing key information on biobanking in cancer, with particular focus on the advantages and risks for patients;

6.3.3 Timeframe

- Month 0: Funding secured for project
- Month 1: establishment of the ECPC -BBMRI-ERIC working group
- Month 3: Drafting of the content for the portal
- Month 5: Production of the content for the portal
- Month 7: Production of the website
- Month 9: launch of the portal

6.4 Immuno-oncology portal (ongoing, confirmed)

Board champions: Francesco De Lorenzo, Kathi Apostolidis, Natacha Bolanos

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 the European Cancer Patient Coalition's most viewed webpages.

The very positive feedback received from ECPC's Membership included some comments on the possible development for the future of the Immuno-Oncology Portal. Our Members have asked for clearer and

updated information on how to access cancer immunotherapies. ECPC intends to answer to this need in 2018 by creating a new Access section on the Immuno-Oncology Portal website.

In 2018, ECPC will launch a new interactive online educational module focusing on the unique side-effects associated with immuno-oncology treatments.

6.4.1 Implementation

ECPC will work with oncology and patient education experts, as well as Flywheel communications, to develop a new interactive online educational module focusing on the unique side-effects associated with immuno-oncology treatments.

6.4.2 Deliverables

- New interactive online educational module on iop.ecpc.org
- Online awareness campaign promoting iop.ecpc.org
- Report on annual usage and update of iop.ecpc.org

6.4.3 Timeframe

- Month 0: Funding confirmed
- Month 1: Project kick-off
- Month 2: Drafting of text
- Month 3: Expert review of text
- Month 4: First draft of interactive module
- Month 5: Second draft of interactive module
- Month 6: Final draft of interactive module
- Month 7: Interactive module approved
- Month 9: Interactive module integrated into iop.ecpc.org
- Month 11: Launch of new interactive module

6.5 ECPC-EORTC seminar on clinical trials (ongoing, confirmed)

Many attempts have been made to centralise and coordinate the existing information on clinical trials. At ECPC we believe that it is necessary to strengthen local patients' associations therefore enhancing their capacity to provide tailor-made answers on clinical trials to a large number of people with cancer.

For this reason, ECPC is glad to continue its collaboration with the [EORTC](#) to co-organise the 2018 edition of the "Understanding Clinical Trials" Seminar. This course is designed specifically for expert cancer patients and patient's advocates, to help them build the understanding necessary to reply to cancer patients' inquiries on clinical trials, such as what are Clinical Trials? How do they work? How does a patient enrol in a clinical trial? What are the pros and cons of being enrolled? What is the EU doing to control clinical trials, safeguard patients' health and promote scientific research?

The goal of this course is to provide high level cancer patient advocates with a stimulating and challenging two-day training experience leading to a much greater understanding of the whole clinical trials process. Participation in this course will enable cancer patient advocates to learn more about cancer biology; personalized cancer treatment and care; the organisation of clinical research; and very importantly, how patient groups can become more involved in the design and implementation of clinical trials.

6.5.1 Timeframe

- October 2017: finalisation of the terms of reference for the project with EORTC
- September 2017: registration opens
- October 2017: invitations sent to speakers
- November 2017: ECPC and EORTC prepare background materials for participants

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- December 2017: registration closes
 - January 2018: participant survey
 - 3 - 4 March 2018: seminar at Radisson Blu in Brussels

6.6 ECPC-EORTC clinical trials portal (ongoing, pending)

Only 5% of all the eligible patients take part in a clinical trial. We believe that the problem resides in lack of information on the risks and advantages of participating into a cancer clinical trial. General information on trials, in fact, provides little added value to cancer patients exactly because of the specific design of clinical trials in cancer.

This gap is widened by the lack of a centralised, harmonised global database of clinical trials in cancer. Information on clinical trials enrolment is scattered across ClinicalTrials.gov, EudraCT and several other national databases. Each of them presents information in different ways, but most often forgetting the basic need of patients for clarity.

ECPC will explore a partnership with the [EORTC](#) to launch two initiatives to address these issues:

1. a web-portal dedicated to explaining to people with cancer what clinical trials are, inspired and guided by the comments and feedback received during the ECPC-EORTC Clinical Trials Seminar;
2. an updated version of the clinical trials search engine, able to pool data from European and international databases and present them in a patient-friendly manner.

6.6.1 Implementation

6.6.1.1 The Portal

Information on clinical trials is out there, already available. So why do people with cancer still experience a knowledge gap? For two reasons: lack of patient-centeredness (and specificity about cancer clinical trials) and lack of harmonisation of information.

The development of the Immuno-Oncology Portal demonstrated that complex scientific information can be translated into comprehensible, patient-friendly information if passed through the filter of expert patients' and patients advocates' scrutiny. The same exercise can be performed for clinical trials, with the advantage that previous attempts to explain clinical trials have more solid roots in cancer patients' advocacy, therefore consolidating the pool of experiences, sources and material from which select the best patient-centric contents.

ECPC will therefore develop an online information platform, divided into 3 main sections:

- **What are clinical trials:** this section explains the basic of clinical trials, from the design of trials, to the different phases of clinical research – it is the core module, from where expert and less expert patients can learn more about the creation and management of clinical trials;
- **Accessing clinical trials:** how do you enrol in a clinical trial? What are pros and cons? This section provides the patients all the elements to make them aware of what does it mean for a patient to be enrolled in a trial, therefore ensuring a truly informed decision; this section will also include a modified version of the already available ECPC Clinical Trials search engine;
- **Clinical trials in Europe:** the impact of clinical trials is not only limited to the individual patients. The implementation of the Clinical Trials Regulation will impact patients' life, but how? This section will follow up the policy around clinical trials, providing expert patients and patients' advocate detailed information on the future of Clinical trials in Europe.

The content will be produced in partnership with EORTC, a leading institution in cancer clinical research, whose independence and experience will have a pivotal importance in ensuring the information provided are both correct and updated to the latest scientific standard.

Independence, scientific correctness, patient centeredness. These are the values on which ECPC will build the Portal. The first two are ensured by the participation of independent scientific experts in the development of the content. But patient centeredness is ensured by several key factors:

- Easy to consult, visually pleasing content: the information provided has to be delivered not only using the language of patients, but also in a way to engage the patient to know more and discover.
- Translations: in a Europe speaking 24+ languages, however, ECPC needs also to ensure that such patient-centric content is translated in as many languages as possible. The language barrier has been consistently mentioned by ECPC's members as their principal problem in sharing ECPC's work at the national level, sensibly dwarfing ECPC's impact at the grassroots level, where help is most needed.

Building on the experience accumulated with the ECPC Immuno-Oncology Portal, ECPC is able to create a series of interactive, patient-friendly online learning modules, which will ensure the content is both engaging and informative.

6.6.1.2 The clinical trials database

ECPC has published, for the first time in Europe, a novel approach to search for clinical trials, via its innovative Clinical Trials Search Engine. While the engine is powerful enough to provide accurate and clear information on cancer trials, it cannot grasp the totality of cancer trials ongoing in the Europe. In fact, the engine pools from the vast ClinicalTrials.gov database, which is unfortunately not fully comprehensive.

EORTC, Europe's leading cancer research organisation, shares ECPC's concerns: patients are just not made aware of all the possible trials they can participate in. The first problem to solve would be to create a tool to provide the informed patients with a complete overview of the opportunities existing.

For this reason, ECPC and EORTC will create a search engine capable of pooling information not only from ClinicalTrials.gov, but also from European and national databases. The winning factor of the ECPC-EORTC search engine will be to provide patients with understandable, simplified and harmonised information on all trials existing in the field of cancer. Our vision is to allow patients to search for trials based on their condition and knowledge of the disease, and to find useful data that they can share with their treating physicians.

To do so, ECPC and EORTC will identify a contractor with the technical capacity to produce such a portal, and will closely monitor and coordinate the production of the search engine. In particular, ECPC and EORTC will ensure that the search engine is easy to use, intuitive and that the results will be presented in a way that patients can understand whether or not the trials can be useful for them.

The search engine will be then made available on ECPC and EORTC websites and on the website of all ECPC's Members willing to provide it to their members.

6.6.2 Deliverables

- An online portal with key information on clinical trials;
- A new clinical trials search engine, able to pool results from European and international clinical trials database and to present information in a clear and uniform way;
- A launch event of the Portal and the Clinical Trials Search Engine, in Brussels.

6.6.3 Timeframe

For the Portal

- Month 0: Funding secured for project
- Month 1: finalisation of the terms of reference for the project with EORTC;
- Month 2: agreement on the final project description, including work plan and deadlines;
- Month 3: production of the first module;
- Month 6: presentation of the draft project to the ECPC Annual General Meeting for evaluation;
- Month 11: delivery of the final version of the portal;
- Month 12: translation in several languages commences.

For the clinical trials search engine

- Month 0: Funding secured for project
- Month 1: definition of the search engine concept and vision;
- Month 3: identification of the contractor;
- Month 4 – Month 8: production of the search engine;
- Month 9: presentation of the search engine.

6.7 Rare cancer patient information (ongoing, pending)

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, and the development of educational tools and learning programmes for the rare cancer patient communities.

6.7.1 Objective

To improve Europeans' understanding of particular rare cancers

6.7.2 Deliverables

- Online education webpage on particular rare cancers for people with cancer and their family (2,500 words)
- Development of educational tools and learning programmes for the rare cancer patient communities
- Printable tri-fold A4 leaflet on particular rare cancers to be disseminated during events related to rare cancers (500-700 words)

6.7.3 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 ECPC educational section of the website. The webpage will include information on causes, risk factors, warning signs, states, treatment options, and prevention guidelines.

Leaflet

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

6.7.4 Timelines:

Month 0: Contract signed

Month 1: Project kick-off

Month 2: Drafting of materials

Month 3: Expert review of content

Month 4: Social media calendar drafted

Month 5: Website content sent for translation

Month 6: Social media calendar approved

Month 7: Review of translations

Month 8: Final approval of website content

Month 9: Website created

Month 10: Month-long social media communication campaign launched

Month 10: Website officially launched

Month 11: Final approval of brochure content

Month 11: Brochures sent for translation

Month 12: Brochures launched

7 Awareness

7.1 New ECPC website (new, confirmed)

Board Champion: Andrew Winterbottom

The website of the European Cancer Patient Coalition is an essential tool to increase the awareness of issues associated with Europeans diagnosed with cancer. It is also a vital source of information for cancer patient organisations within Europe. It contains an up to date summary of relevant news, as well as educational resources and policy documents. However, the structure of this website has not been upgraded since 2013. The European Cancer Patient Coalition is in need of a new website that is mobile- and tablet-friendly, as well as allowing a better structure to reflect the wealth of information available.

Objectives

- To improve the website of the European Cancer Patient Coalition

Deliverables

- Updated responsive website that is mobile- and tablet-friendly

Timelines

- Month 0: Financing secured and contract signed
- Month 1: Google Analytics Report of existing website
- Month 2: Work with IT company to obtain technical recommendations for creating a new responsive website
- Month 3: Draft site architecture map for new responsive website
- Month 4: Finalise site architecture map for new responsive website
- Month 5: Wireframes for new responsive website
- Month 6: Review of homepage designs for new responsive website
- Month 8: Review of inner page designs for new responsive website
- Month 9: Testing of new responsive website
- Month 11: Migration to new responsive website
- Month 12: Launch of new responsive website

7.2 World Cancer Day (ongoing, confirmed)

Board Champion: Andrew Winterbottom

The Union for International Cancer Control, promoter of the World Cancer Day, states that:

Taking place under the tagline 'We can. I can.', World Cancer Day 2016-2018 will explore how everyone – as a collective or as individuals – can do their part to reduce the global burden of cancer.

Just as cancer affects everyone in different ways, all people have the power to take various actions to reduce the impact that cancer has on individuals, families and communities.

World Cancer Day is a chance to reflect on what you can do, make a pledge and take action. Whatever you choose to do 'We can. I can.' Make a difference to the fight against cancer.

ECPC will support and amplify UICC's message by:

- Developing a social media calendar to schedule messages on and around World Cancer Day
- Promoting World Cancer Day messages in multiple European languages
- Joining the "Talking Hands" campaign on Twitter and Facebook
- Joining the World Cancer Day Thunderclap on Twitter
- Promoting World Cancer Day in the News section of the ECPC website

7.3 Nutrition and physical activity campaign (ongoing, confirmed)

Board Champion: Francesco De Lorenzo

Nutrition is a crucial component 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 is often neglected, leaving people with cancer and their family with doubts, questions and the need for practical guidance on how to eat better on a daily basis, especially during therapy.

In 2015 ECPC sent out an extensive survey on physical activity and nutrition and their importance on the treatment and life of people with cancer. The results were presented during the ECPC Annual Congress 2015 in Brussels. The preliminary data obtained from the survey suggested that discrepancies still exist between the patients' expectations/demands, and the answers they may get from physicians about the metabolic and nutritional issues in cancer.

In 2016 ECPC continued ECPC's efforts with a second round of the survey in order to have enough data and maximise the impact of the answers received. The new ameliorated version was adapted in order to directly address individual people with cancer and cancer survivors. Generally, the overall preliminary data underscores the need to implement education among patients but also among healthcare professionals in order to improve nutritional care.

After the first report, ECPC in collaboration with nutrition experts developed a scientific paper on nutrition, based on empirical data, which was presented at the 2017 Annual Meeting and will be submitted to a peer-reviewed journal. The paper provided a solid basis for the development of patient friendly information material on nutrition. Indeed, people with cancer need to have the tools to ask more from their clinicians, who unfortunately demonstrate to neglect the nutritional needs of people with cancer. The European Cancer Patient Coalition has successfully submitted a **Nutrition abstract of the paper**, where ECPC will be presenting **poster #1450P at the ESMO 2017 Congress in Madrid on 10 September at 1:15 pm in Hall 8**, and featured abstract in the ESMO 2017 Congress Book – supplement of the Annals of Oncology.

Additionally, ECPC produced a charter of rights of people with cancer for appropriate and early nutritional support. This charter is a key advocacy tool for patient organisations at national level. ECPC will be hosting an event in November 2017 at the parliament where the Charter will be brought forward along with Nutritional material developed for cancer patients.

In 2018, ECPC will promote the importance of nutrition and physical activity during a month-long advocacy campaign.

7.3.1 Implementation

7.3.1.1 Awareness Campaign

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 European Society for Clinical Nutrition and Metabolism Guidelines for People with Cancer will be translated into simple messages that will be disseminated using a social media campaign.

Building upon the educational materials it developed in 2017, ECPC will produce a Nutrition and Physical Activity Awareness Month toolkit for patient organisations. ECPC will partner with an agency such as Porter Novelli, Cheil Belgium, or Cambre Associates to produce a toolkit that includes a Thunderclap, Twibbon, and social media calendar. 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 better nutrition and physical activity for people with cancer.

7.3.1.2 Webpages

Building upon the activities listed above, the ECPC policy and education webpages on nutrition and physical activity will be updated.

Policy webpage

Based on input from experts, the policy webpage will contain sections such as:

- Information about the ECPC Nutrition Advocacy and Physical Activity Campaign
- Link to the 2017 ECPC Scientific Paper on Nutrition and Physical Activity
- Link to the Charter of Rights for Nutritional Support

Patient education webpage

Building upon the results from the survey, an educational webpage will be created, with patient information and advice website on nutrition and physical activity. This will be produced in conjunction with experts, and will contain sections such as:

- Education about nutrition and physical activity
- Important questions to ask your doctor about nutrition and physical activity
- How do I get in touch with my nearest patient organization?

7.3.2 Deliverables

- Nutrition and physical activity awareness month toolkit
- Awareness campaign
- Improved nutrition and physical activity policy webpage
- Improved nutrition and physical activity patient education webpage

7.3.3 Timeframe

January 2018: Nutrition and physical activity awareness month toolkit

March 2018: Nutrition and Physical Activity Awareness Month

November 2018: Launch of updated policy and education webpages

7.4 Bladder cancer campaign (ongoing, confirmed)

Board Champion: Andrew Winterbottom

The ECPC Paper on Bladder Cancer was drafted by ECPC Expert Group on Bladder Cancer, and launched in April 2016, in collaboration with ECPC members such as Action Bladder Cancer UK, Fight Bladder Cancer UK, and Associazione PaLiNUro Italy.

In 2017, 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 2018, 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.

7.4.1 Objectives

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

7.4.2 Implementation

7.4.2.1 Urology Cancer Advocacy Session

The ECPC will co-cost a Patient Advocacy Session at the European Association of Urology congress in Copenhagen on Sunday 18 March. 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.

Draft agenda:

09:00–10:30 **European Reference Network eUrogen**

10:30–11:00 **In-room coffee break with finger food**

11:00–11:45 **Round Table: The unmet needs of urology cancer survivors**

Prostate cancer (Ken Mastris, Europa Uomo)

Bladder cancer (Andrew Winterbottom, Fight Bladder Cancer & ECPC)

Kidney cancer (Michael A. S. Jewett/ Deb Maskens / Rachel Giles, International Kidney Cancer Coalition)

11:45–12:30 **Involving the patient**

How to use make patient information more understandable (Michael van Balken / F. Schlatmann, Easy Peesy, Rijnstate Hospital, Netherlands)

How to access EAU Patient Information Tools in your language (Thorsten Bach, EAU)

How communication between patients and nurses influence health outcomes (Corinne Tillier, EAUN)

12:30–13:00 **Keynote speeches**

Community-level cancer care (Tit Albreht, CanCon)

How to increase the impact of an awareness campaign (Andrew Winterbottom / Lydia Makaroff, ECPC)

How to use policy papers to call for change at the pan-European level (Hendrik Van Poppel, EAU)

How to move forward with a white paper on kidney cancer (Michael A. S. Jewett / Deb Maskens / Rachel Giles, International Kidney Cancer Coalition)

13:00 – 14.00 **Break-out session**

Session A: Development of a Pan-European awareness campaign on urological diseases

Session B: Development of a white paper on kidney cancer

14:00-15:00 **Networking coffee**

7.4.2.2 Patient Experience Survey

The European Cancer Patient Coalition will present the results of the 2017 Patient Experience survey at the European Association of Urology congress in Copenhagen in March 2018, and at the Fight Bladder Cancer Bladder booth at the British Bowel Surgeons conference in June 2018.

The results of the survey will also be explored in a special supplement in Fight Bladder Cancer's magazine "*Fight*", which will be published during Bladder Cancer Awareness Month in May 2018. "*Fight*" magazine is the only magazine for people affected by and working with bladder cancer, and has a combined print and online readership of over 60,000 people per edition.

7.4.2.3 Awareness Campaign

The month of May is Bladder Cancer Awareness Month. We remember all those who have lost their fight with this disease, but it is also a time when ECPC stand together for those currently undergoing treatment and everyone who is affected by bladder cancer.

Building upon its successful social media campaign in 2017, ECPC will produce an enhanced Bladder Cancer Awareness Month toolkit for patient organisations. ECPC will partner with an agency such as Porter Novelli, Cheil Belgium, or Cambre Associates to produce a toolkit that includes a Thunderclap, Twibbon, template for public event, and social media calendar. 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 Bladder Cancer supporters to work toward.

Bubbles for Bladder Cancer is an annual event for people across the world affected by bladder cancer, initiated by Fight Bladder Cancer UK. At noon on the last Sunday in May, ECPC will work with Fight Bladder Cancer UK and other bladder cancer organisations all over the world to produce a blanket of bubbles in public places and online to recognise people with bladder cancer and call for better awareness and outcomes.

7.4.2.4 Webpages

Building upon the activities listed above, the ECPC policy and education webpages will be updated.

Policy webpage

Based on input from the ECPC Bladder Cancer Advocacy Working Group, the policy webpage will contain sections such as:

- Information about the ECPC Bladder Cancer Advocacy Working Group
- Link to the 2016 ECPC White Paper on Bladder Cancer
- Updated policy recommendations

Patient education webpage

Building upon the results from the survey, an educational webpage will be created, with patient information and advice website on bladder cancer. This should be produced in conjunction with EU based professional bodies such as the European Association of Urology. It will contain sections such as:

- Education about bladder cancer
- What are the symptoms of bladder cancer?
- How do I find a doctor?
- How do I get in touch with my nearest bladder cancer patient organization?

7.4.3 Deliverables

- Urology cancer patient advocacy session report
- Bladder cancer awareness month toolkit
- Improved Bladder cancer policy webpage
- Improved Bladder cancer patient education webpage
- Awareness campaign

7.4.4 Timeframe

- February 2018: Bladder cancer awareness month toolkit
- March 2018: Urology cancer patient advocacy session at EAU Copenhagen
- May 2018: Bladder Cancer Awareness Month
- November 2018: Launch of updated policy and education webpages

7.5 Make sense of head and neck campaign (ongoing, pending)

Board Champion: Natacha Bolanos

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 2018 Make Sense campaign, ECPC will organise an event in the European Parliament to promote awareness of these cancers and call for prevention, standardised care, and better quality of life for people with cancer and cancer survivors.

7.5.1 Implementation

Event in the European Parliament discussing head and neck cancers

Proposed topic:

- **Multidisciplinary treatment.** Due to the many factors involved in making an optimal, patient-centred treatment decision and the complex nature of the disease, input and expertise is required from a number of specialised physicians, such as: medical oncologists, radiation oncologists, head and neck surgeons, radiologists, oncology nurses, speech therapists, social workers, psychologists, plastic and/or reconstructive surgeons and dentists with particular interest and expertise in head and neck cancer. In the four member states currently offering multidisciplinary care (France, Belgium, The Netherlands and UK) benefits for both patient and physician have been observed.

7.5.2 Timeframe

- June 2018: Preparations begin
- September 2018: Event in the European Parliament

7.6 Biomarker awareness month (ongoing, confirmed)

Board champions: Francesco De Lorenzo, Jana Pelouchova

Cancer molecular profiling and other types of biomarker testing are 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 and the European Alliance for Personalised Medicines carried out a biomarkers survey from people with cancer, 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 will produce a detailed webpage and infographic on biomarkers. The infographic will be available as a website and a downloadable pdf. This will be followed by an event at the European Parliament to discuss with experts in the field of biomarkers.

In 2018, ECPC will promote the importance of cancer molecular profiling and other types of biomarkers during a month-long advocacy campaign.

7.6.1 Objectives:

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

7.6.2 Implementation

7.6.2.1 Awareness Campaign

The month of October is Personalised Medicine Month, where we stand together to increase the awareness of the importance of biomarkers and other aspects of personalised medicine. ECPC will work

with the European Alliance for Personalised Medicines to translate the importance of biomarkers into simple messages for people with cancer that will be disseminated using a social media campaign.

Building upon the educational materials it developed in 2017, ECPC will produce a Personalised Medicine Month toolkit for patient organisations. ECPC will partner with an agency such as Porter Novelli, Cheil Belgium, or Cambre Associates 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.

7.6.3 Deliverables

- Personalised medicine awareness month toolkit
- Awareness campaign

7.6.4 Timeframe

June 2018: Personalised Medicine month toolkit

October 2018: Personalised Medicine Month

7.7 Pancreatic cancer campaign (ongoing, confirmed)

7.7.1 World Pancreatic Cancer Day

Board champions: Kathi Apostolidis, Natacha Bolanos

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, promoting World Pancreatic Cancer Day messages in multiple European languages, joining the World Cancer Pancreatic Day Thunderclap on Twitter, and promoting World Cancer Day in the News section of the ECPC website.

7.7.2 Pancreatic Cancer Europe

The Director of the 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 ECPC will be a speaker at the Pancreatic Cancer Europe meeting at the European Parliament in November 2018, 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.

7.7.3 Timeframe

- November 2018: World Pancreatic Cancer Day
- November 2018: Pancreatic cancer event at the European Parliament
- December 2018: Publication of the World Pancreatic Cancer Day report.

8 Advocacy

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

Board champions: Francesco De Lorenzo, Kathi Apostolidis, Dan Cimpoeru

The European Cancer Patient Coalition is involved in the European Commission's 2018 Innovative Partnership Action against Cancer. The specific objectives and deliverables concerning cancer patients are established by ECPC in collaboration with all the other partners, and will be finalised by the end of 2017.

8.2 Biosimilar policy paper (new, pending)

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. Biosimilars (similar versions of the originator biologics) present a necessary opportunity for physicians, patients and healthcare systems, and may increase access to medicines by improving financial sustainability of health care systems. However, policies must be implemented to ensure that people with cancer are prescribed the safest and most efficacious treatment possible. For example, there are issues around the switching and substitution of biological treatments. ECPC recommends that any decision to change or switch should be jointly taken by the physician and the patient, patients should be closely monitored at all times, and that pharmaco-vigilance is essential.

In 2018, ECPC will draft a policy paper, in collaboration with its Members, the Legal Network of Cancer Patients, and other European experts, to distil the policy recommendations to protect and empower people with cancer in relation to biosimilars.

8.2.1 Deliverables:

- Policy white paper on biosimilars

8.2.2 Timeline:

- January 2018: Identification of authors and reviewers
- March 2018: Table of contents
- May 2018: First draft
- July 2018: Review by ECPC members
- September 2018: Final draft
- December 2018: Launch of ECPC policy white paper on biosimilars

8.3 Cancer-associated thrombosis & supportive care roundtable (new, confirmed)

Board champions: Kathi Apostolidis, Natacha Bolanos

8.3.1 Aim of project

For the European Cancer Patient Coalition and the European Oncology Nursing Society to hold a roundtable event with policymakers and health professionals to discuss and promote the importance of cancer-associated thrombosis and supportive care.

8.3.2 Objectives:

- To promote the importance of cancer-associated thrombosis and supportive care to cancer patients and oncology nurses in Europe
- To raise awareness of the important role that oncology nurses play in cancer treatment

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- To promote educational resources about cancer-associated thrombosis and supportive care for oncology nurses and cancer patients
 - To educate policy makers of the importance of cancer-associated thrombosis and supportive care

8.3.3 Description:

As pointed out in the Cancer-Associated Thrombosis Whitepaper there is a lack of information for cancer patients. Especially there are 4 main issues:

- When an oncologist obtains a patient's consent for cancer therapy he usually informs about typical side effects of cancer therapy, e.g. hair loss, infection, nausea but not about cancer-associated thrombosis.
- Patients don't know whether they have a risk of cancer-associated thrombosis and whether it is high or low.
- Patients don't know (and are not informed) about the typical symptoms of cancer-associated thrombosis and what to do, when they occur (e.g. where/who to call and what to tell).
- During the course of their treatment patients are regularly asked about fever and nausea but they are not regularly assessed for symptoms of cancer-associated thrombosis.

Oncology nurses are crucial in this aspect as they have the daily contact with the cancer patient. Therefore, they need to have the right conditions, education and tools at hand to give the proper information and guidance to cancer patients in relation to cancer-associated thrombosis and supportive care throughout the patients' treatment pathway.

To address this issue the European Cancer Patient Coalition will conduct a roundtable with the European Oncology Nursing Society. Such a seminar could also include the invitation of a few key Members of the European Parliament and could take place in a hotel near the European Parliament. Furthermore, the European Cancer Patient Coalition will also include experts in the field of cancer-associated thrombosis, and national representatives from European Oncology Nursing Society. A total participant number between 8-15 participants would allow for range in participation whilst still making discussion and decision on some calls to action possible.

8.3.4 Deliverables

The roundtable will have a clear, tangible outcome in the form of a short report with a set of recommended actions on next steps on how to optimize the role of cancer nurses in cancer-associated thrombosis patient management. An after the event report will be distributed among key stakeholders and participants would be the basis of further advocacy activities, and will give foundation for further actions.

8.3.5 Timeframe

- October 2018: Finalisation of agenda
- November 2018: Invitations to the event participants and speakers
- December 2018: Preparations of presentations and speaker biographies
- January 2018: Promotion of event
- Late January/ early February 2018: Event in Brussels
- March 2018: Event report

8.4 Cancer-associated thrombosis & supportive care survey (new, confirmed)

Board champions: Kathi Apostolidis, Natacha Bolanos

8.4.1 Aim of project:

ECPC to conduct a cancer-associated thrombosis patient baseline study in their organisation to get a picture of the knowledge of cancer-associated thrombosis and supportive care among cancer patients.

Description

In the Roadmap of the Cancer-Associated Thrombosis Whitepaper, one of the preferred actions of the cancer-associated thrombosis whitepaper expert group was to conduct a patient survey to measure awareness of cancer-associated thrombosis among cancer patients. More specifically the Roadmap states that:

A patient survey should be undertaken to measure the level of awareness of cancer-associated thrombosis among cancer patients, including a mapping of where patients get their information about cancer-associated thrombosis. This could be done in one or more countries in one/more parts of the world. Such a survey could be developed into a publication and published. This would give a baseline for the expert group's work and would also be a helpful tool to engage in conversation with stakeholders, especially patients and health professionals.

8.4.2 Proposal

Cancer and its treatments (surgery, hospital admissions, chemotherapy, the presence of indwelling catheters) are recognised risk factors for venous thrombosis. Cancer-associated thrombosis is a very common complication in cancer patients, but relatively little understood. Approximately 4% to 20% of people with cancer experience venous thrombosis – 4 to 5 times higher than in the general population. Cancer-associated thrombosis, and associated complications, have significant adverse impacts on quality of life for those who are suffering from it; and they are the second most frequent cause of mortality in cancer patients.

Little – if any – work has been undertaken to understand cancer patients' awareness of thrombosis, of these risk factors, of symptoms, or of possible treatments. This important study therefore seeks to develop a new evidence set through a patient survey that will establish:

- The level of awareness of cancer-associated thrombosis among cancer patients
- A mapping of where patients get their information about cancer-associated thrombosis.
- A final summary of the gaps in information, support etc. during the patient pathway highlighting where action needs to be undertaken, e.g. calls to action on the basis of the findings.

This survey will also be a tool to demonstrate towards policymakers and health professionals where more needs to be done to raise the awareness about cancer-associated thrombosis and supportive care among cancer patients.

To do this, the European Cancer Patient Coalition will work with an organisation such as Quality Health to develop a three-stage process:

- the development and testing of a survey tool (an online questionnaire)
- patient survey fieldwork in European countries

-
- thorough analysis of the findings of all of the above.

This proposal aims to publish findings in time for World Thrombosis Day on 13th October 2018.

This proposal includes thorough Cognitive Testing of a pilot UK questionnaire, to ensure that question and answer sets are understandable, relevant and comprehensive to cancer patients. This will be followed up with further Cognitive Testing in the other countries, to ensure that questionnaires and question sets remain relevant in other healthcare systems and settings.

8.4.3 Timelines

- October, November, December 2017: Design, development and testing of pilot (UK) questionnaire.
- January, February, March 2018: UK survey fieldwork.
- February, March, April 2018: Design, development and testing in other European countries
- April, May, June 2018: European survey fieldwork
- July, August, September 2018: Final data analysis and report production
- 13 October 2018: Final data and report available, and final presentation

8.4.4 Deliverables

- An interim written report from the UK pilot
- Publicly available final written report following the surveys in other countries

8.5 Joint Action on Rare Cancers (ongoing, confirmed)

Board champions: Francesco De Lorenzo, Jana Pelouchova

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): three 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 is honoured to contribute and represent the needs, rights and hopes of people with rare cancers in the Joint Action on Rare Cancers (JARC): **The European Cancer Patient Coalition 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

Website: <http://www.ecpc.org/activities/working-groups/177-wgrc>

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 ECPC Annual Congress 2016, ECPC has 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. **ECPC will build on experience gained during its 3 years collaboration in the RARECAREnet project.**

8.5.1 Implementation

The key objective of the Working Group on Rare Cancers is to give ECPC Members and non-members with an interest in rare cancers the opportunity to formally and directly contribute and collaborate in the work of the JARC and to offer them a platform to share their knowledge and cooperatively generate expertise to respond to the JARC needs and requests.

In addition to their contribution to the JARC, the Working Group on Rare Cancers members will also have the opportunity to use the platform to decide on further topics for discussion, of interest to people with rare cancers, e.g. the ERN implementation, the Orphan Drugs Regulation and the Paediatric Regulation. The aim of the Working Group on Rare Cancers is to provide its members and all ECPC members with a practical and effective instrument to react to the European and national policy challenges related to rare cancers. Every ECPC Member (Full and Associate) and non-members active in rare cancers can join the WGRC that will meet in person once a year during the Annual Congress. The Working Group on Rare Cancers will also meet at least 2 times a year via teleconference.

ECPC will ensure the dissemination of the activities of the Working Group on Rare Cancers, including all the documents approved by the Working Group on Rare Cancers. ECPC will offer administrative and policy formulation support to the Working Group on Rare Cancers.

8.5.2 Timeframe

- February 2018: Videoconference meeting of the Working Group on Rare Cancers
- June 2018: Annual meeting of the Working Group on Rare Cancers during the ECPC Congress
- September 2018: Development of educational tools and learning programmes for the rare cancer patient communities
- October 2018: Videoconference meeting of the Working Group on Rare Cancers

8.6 Legal Network for Cancer Patients (ongoing, confirmed)

Board Champion: Dan Cimpoeu

ECPC has established a Pan-European network of volunteer legal practitioners that will reinforce the advocacy work of the ECPC and people with cancer with legal instruments. In 2017 ECPC created the Legal Network for Cancer Patients. It is a group of legal practitioners that aim to share their legal competences to the benefit of people with cancer on a volunteer basis.

The Legal Network for Cancer Patients will engage in core activities, aimed at raising ECPC's capacity to produce meaningful legal support to its members. Furthermore, the Legal Network for Cancer Patients will continue focus on three key legal issues where ECPC can create added value for its members.

8.6.1 Core activities

8.6.1.1 Monitoring Compliance with the EU Legislation by the Member States

"Public Health" is regulated by art. 168 of the Treaty on the Functioning of the European Union. "Public Health" is a competence shared between Member States and the EU. EU legislation needs to be transposed into Member States' national law by the deadline set out in the legislation. Often, national authorities experience considerable transposition difficulties and the law is not adequately implemented.

The Legal Network for Cancer Patients will act as a "legal watchdog" in cases of doubtful transposition. ECPC Board might, at the request of the Legal Network for Cancer Patients, adopt a position and make a statement on the issue at stake.

8.6.1.2 Defending Patients' rights when EU Legislation is breached by the Member States

In 2014-2015, based on the art. 6 (1) of the European Directive 89/105/EEC of 21 December 1988, the Romanian Federation of Cancer Patients Associations (FABC), with the support of ECPC Board Member Dan Cimpoeu, won 17 lawsuits against the Romanian government resulting in 165 people with cancer now receiving medical treatment for free. This is a real example of how ECPC can build a national lawsuit based only on the EU rules. Starting from this, the Legal Network for Cancer Patients could provide legal assistance for national NGOs.

8.6.1.3 Sharing Legal Best Practices

The Platform will allow practitioners to exchange best practices from action settlement to lawsuit litigation and communication around the cases taken to court.

8.6.1.4 A Legal Professional Background for ECPC Positions

As an umbrella organization ECPC is often requested to express official positions on different papers/issues. ECPC positions would be stronger if legally documented. The Legal Network for Cancer Patients lawyers support ECPC advocacy work with legal arguments to reinforce some of its messages.

8.6.2 Deliverables

- Webpage listing members of the Legal Network for Cancer Patients and their work

8.6.3 Timeframe

- June 2018: Face-to-face meeting of the Legal Network for Cancer Patients

9 Capacity-building activities

9.1 Shared decision-making workshop (new, pending)

Board champion: Kathi Apostolidis

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.

Speakers may include representatives from the European Organisation for Research and Treatment of Cancer, the Informed Medical Decision Making Foundation, Maastricht University, Cardiff University, or Dartmouth University.

9.1.1 Deliverables

- Shared decision-making workshop
- Report on shared decision-making workshop

9.1.2 Timelines

- Month 0: Funding secured
- Month 1: Project kick-off
- Month 2: Agenda drafted
- Month 3: Agenda finalised
- Month 4: Speakers invited
- Month 5: Participants invited
- Month 8: Shared decision-making workshop
- Month 9: Report on shared decision-making workshop

9.2 ECPC Annual Congress 2018 (ongoing, confirmed)

Board Champions: Francesco De Lorenzo, Kathi Apostolidis, Jana Pelouchova, Andrew Winterbottom, Natacha Bolanos

The ECPC 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 ECPC Annual Congress has increased its capacity and scope, with over 150 participants in 2016 and 2017.

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 2018 Action Plan will occur during the Annual Congress, including:

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

The ECPC Annual Congress will take place in June 2018, in Brussels, Belgium.

9.3 ECPC newsletter (ongoing, confirmed)

Board Champion: Andrew Winterbottom

In 2014 ECPC kicked off a newsletter service to inform ECPC Members and stakeholders of all the initiatives of the organisation. Through the months, the newsletter built up confidence in the ECPC Membership, and was instrumental in the increase of participation of ECPC Members in the activities of the association. More than 700 email addresses national and European cancer patients' organisations and other stakeholders are included in the newsletter database. Thanks to Mailchimp, ECPC's newsletter system, ECPC can monitor and analyse what ECPC's Members find more interesting, which consolidates ECPC's understanding of the ECPC Membership's needs. Therefore, ECPC have consolidated and nurtured a very successful newsletter system that reaches some of the most committed cancer patients' advocates in Europe and that has been continuously providing useful information on the ECPC activities.

In 2018 ECPC will continue to provide ECPC's 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 the European Cancer Patient Coalition also actively participates in several of the European Union's Research and Innovation framework programmes, such as IMI 1 projects, the Seventh Framework Programme (FP7) and IMI 2 projects under the current Horizon 2020 (H2020). In 2017, 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 2018.

9.3.1 Implementation

The ECPC Newsletter will cover news and information regarding ECPC's activities and projects. The ECPC Newsletter will be produced by the Community and Communications Manager, in collaboration with the Head of EU Affairs and the Project Coordinator, and under the final supervision of the Director. The Community and Communications Manager will be responsible of collecting news and information on ECPC's activities and to draft articles to be included in the newsletter.

ECPC will produce a newsletter containing the most important news once every month.

9.3.2 Deliverables

- 12 ECPC Newsletters in 2018.

5.2.4. Timeframe

- January – December 2018: production of 12 ECPC Newsletters (once a month)

9.4 Building a sustainable internship programme (ongoing, confirmed)

Board champion: Andrew Winterbottom

Thanks to the ECPC Secretariat, ECPC managed to increase the number of quality of ECPC's initiatives greatly since 2013. However, the increasing budget and responsibilities need to be supported with appropriate staffing. For this reason, in 2018 ECPC will continue to offer solid internship programme to support the policy and communication work. ECPC will facilitate and prioritise the application from young cancer survivors.

10 Collaborations

10.1 OEI (ongoing, confirmed)

Board champions: Francesco De Lorenzo, Jana Pelouchova

The signature of a Memorandum of Understanding in September 2015 between ECPC and [Organisation of European Cancer Institute \(OEI\)](#) marked a milestone for cancer advocacy: ECPC formally joined forces with the organisation reuniting Europe's best oncology centres. This incredibly powerful partnership effectively represents all those that try to win the fight against cancer using the best tools at ECPC's disposal.

The first implementing act of the Memorandum of Understanding was the creation, launch and implementation of a Joint Declaration on Good Relational Practices in Cancer Care and Research (simply referred as "Joint Declaration").

10.1.1 The Joint Declaration

The Joint Declaration outlined the vision that ECPC and OEI share regarding how patients and cancer centres can interact to enhance the patients' quality of life. By implementing the values of the Joint Declaration, cancer centres and patients' organisations can build better and more meaningful relationships, ultimately ameliorating the way they collaborate for the final benefit of the patients.

Through the Joint Declaration, ECPC and OEI are trying to **respond to the increasing demand for guidance and support in better involving patients in the life of the cancer centre**. Hospital testimonies, ethical frameworks, patients' charters and policy recommendations never fail to mention the central role of patients. However, in practice, there is little guidance on how to truly better include patients in the decision-making process at hospital level. ***The main mission of the Joint Declaration is to give guidance to patients, patients organisations and cancer institutes on how to better build their relationship to support everyone's needs and rights.***

The Joint Declaration is therefore composed of two main documents:

- **The Joint Declaration** itself: a series of key statements describing the **principles** on which the collaboration among patients, patients' organisations and cancer centres should be based, and pointing at the **objectives** that such collaboration can achieve;
 - The three principles are:
 - **Atmosphere**: the cancer centre is an environment where care is provided, research is performed, and which is open to dialogue;
 - **Synergy**: cancer centres, patients and patients' associations can grow together by building capacities that complete each other's mission;
 - **Integration**: roles within the cancer centres should be redefined to satisfy the first two principles. Feedbacks, sharing of information, thoughts and emotions should be fully integrated in the collaboration to increase mutual understanding.
- **The practical aims**: a series of examples of how that relationship among patients, patients' associations and cancer centres can be improved. There are concrete objectives that can be achieved by working together, like:
 - Improving the informed consent forms;
 - Improve participation to clinical trials;
 - Helping patients by educating and supporting his/her relatives;
 - Survivorship;
 - Improve the collection of sample for biobanks;

Following this structure, the Joint Declaration is a living document. While the three principles will remain the same, ECPC and OEI can add new aims at any time, following the interest and needs of both Memberships. This makes the Joint Declaration time-proof and also easily adaptable to the new needs and new rights of people with cancer.

10.2 ESMO (ongoing, confirmed)

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

In June 2016, the European Cancer Patient Coalition (ECPC) and the European Society for Medical Oncology (ESMO) signed a Memorandum of Understanding, with the aim of enhancing the existing cooperation and increasing the efforts to achieve their common goals and objectives in the field of cancer to satisfy the new needs and new rights of people with cancer across Europe.

The Memorandum formalises a long-established partnership. ECPC and ESMO have collaborated on a large range of key policy issues related to cancer, including:

- The update of ESMO Guidelines;
- The update of the ESMO Handbook on cancer survivorship.

In 2018, ECPC and ESMO will work to implement the agreement and commitments taken in 2016.

10.2.1 ESMO Guidelines

ECPC is directly involved in the drafting of the updates of the new [ESMO Clinical Practice Guidelines](#). Updated regularly by the [ESMO Guidelines Committee](#), the Guidelines are the standard for best practice of a vast variety of cancers, and represent the most reliable, evidence based resource to help oncologists in taking practical decisions that affect patients' lives. ECPC and ESMO decided to partner up to include more patient-friendly and solid information in the guidelines. In the coming years, each updated ESMO Guideline will contain a reviewed, patient-oriented survivorship chapter. At the same time, ECPC will publish on its website all [ESMO Guides for Patients](#), an invaluable source of information, which is often overlooked by those that could benefit the most from them. ECPC and ESMO will also ensure that the Guides for Patients will include updated provision on survivorship care, in line with the Clinical Guidelines.

10.2.2 Handbook on survivorship

More than 10 million European citizens are currently living with a diagnosis of cancer. Cancer incidence is on the rise: last year 3.75 million new people with cancer have been diagnosed. At the same time, thanks to the advancements in cancer treatment and the amelioration of standards of care, cancer mortality is decreasing. This situation, paired with the ageing of the European population, results in a large number of cancer survivors, with specific needs that the cancer community is not adequately addressing, such as:

- **The stigma of cancer** – The European Union and national governments have the responsibility to debunk the myth “cancer=death”, which is stigmatising millions of Europeans and creates unacceptable discrimination;
- **Survivorship cancer plan** - The need for a structured, multidisciplinary and integrated survivorship care plan has been strongly underlined by the recommendations of the Joint Action on Cancer Control (CanCon), to help the oncologists to follow up people with cancer after the acute treatment phase;
- The need for tools to **implement and disseminate** such survivorship cancer plans, like templates, mobile applications and other instruments to monitor the survivorship care of people with cancer and allowing them to return to a normal life.

ECPC and ESMO will continue to update the ESMO Handbook on survivorship, a practical, hands-on publication used by thousands of oncologists in Europe. Furthermore, ECPC and ESMO will publish a patient-friendly version of the handbook.

10.3 UICC (ongoing, confirmed)

Board champion: Francesco De Lorenzo, Dan Cimpoeru

The Union for International Cancer Control (UICC) is a membership organisation that exists to help the global health community accelerate the fight against cancer. Founded in 1933 and based in Geneva, UICC's growing membership of over 900 organisations across 155 countries, features the world's major cancer societies, ministries of health, research institutes and patient groups. Together with its members, key partners, the World Health Organization, World Economic Forum and others, UICC is tackling the growing cancer crisis on a global scale.

Following a series of meetings between ECPC and UICC leaderships, ECPC was invited to become a UICC Member. ECPC has been a Full Member of the Union since 2015, and keeps close ties with the leadership to identify future areas of collaborations between ECPC and UICC in Europe and beyond.

In 2018, ECPC will participate in the World Cancer Congress in Kuala Lumpur from 1-4 October.

11 EU projects

11.1 European Reference Networks - EURACAN (ongoing, confirmed)

Board champion: Jana Pelouchova

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 a rare or complex conditions from 2017 to 2021.

ECPC is one of the patient organisations representing the needs, rights and hopes of adults with rare solid cancers as a European Patient Advisory Group Representative under the European Reference Network for rare solid cancers (EURACAN). The EURACAN European Reference Network gathers all rare adult solid cancers which are grouped in 10 domains corresponding to the RARECARE and RARECARENet 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 and ECPC is co-chairing the Taskforce under Communication and Dissemination.

11.2 IMI DO-IT Big Data 4 Better Outcomes (ongoing, confirmed)

Board champions: Dan Cimpoeru, Natacha Bolanos

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. This project will run from 2017 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 will be involved in dissemination and communication (WP3) and in the development of the Informed Consent Forms and the training materials (WP4).

11.3 IMI PREFER patient preferences (ongoing, confirmed)

Board champions: Francesco De Lorenzo, Kathi Apostolidis

The project PREFER, funded by the Innovative Medicines Initiative (IMI), is a 5 year project with a main objective to 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, HTA 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 will run from 2016 to 2020.

Within the project ECPC will lead the Patient Advisory Group with the other patient organisations involved (namely MDUK, EPF and IAPO), will provide feedback on patient preference elicitation issues and approach, will help in the drafting of recommendations and will deal with dissemination activities with an event at the end of the project.

11.4 ELBA European Liquid Biopsy Academy (ongoing, confirmed)

Board champion: Andrew Winterbottom

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. The European Liquid Biopsy Academy (ELBA) is an Innovative Training Network that will educate early stage researchers with the skills to circumvent the obstacles currently hampering effective development and commercialisation of liquid biopsy approaches. It 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. The project will run from 2018 to 2021.

The European Cancer Patient Coalition 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. The European Cancer Patient Coalition will also participate in workshops on communicating complex research results to a public audience, understanding the patient perspective, and on scientific writing.

11.5 H2020 IMMUNISA cervical cancer vaccine (ongoing, confirmed)

Board champion: Natacha Bolanos

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 will be involved in Work Package 6: Project Management & Dissemination. ECPC will review 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.

11.6 H2020 ImmunoSABR metastatic lung cancer (ongoing, confirmed)

Board champion: Matti Jarvinen

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 2016 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 (clinicaltrials.gov no. NCT02735850). 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, the European Cancer Patient Coalition 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.

11.7 H2020MM04 / DENIM mesothelioma (ongoing, confirmed)

Board champion: Kathi Apostolidis

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 will be involved in Work Package 6, the Work Package responsible for the effective dissemination of the results to external stakeholders. ECPC will disseminate the project news and results to all its Member patient organisations via the ECPC newsletter as well as via the 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.

11.8 Transcan-2 European Research Area (ongoing, confirmed)

Board champions: Francesco De Lorenzo, Kathi Apostolidis

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.

11.9 eSMART mHealth symptom management (ongoing, confirmed)

Board champion: Kathi Apostolidis

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.