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# European Cancer Patient Coalition Action Plan 2017

Consolidating ECPC's position in Europe



EUROPEAN  
CANCER  
PATIENT  
COALITION



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## Why partner with ECPC?

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

## ECPC objectives for 2017

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 senior Board Members with previous experience (3 out of 7). Furthermore, an Audit Committee has been established and Scientific Committee will be established to ensure the sound financial management and scientific integrity of ECPC in 2017 and beyond. In late 2016, we will integrate the contribution, energy and ideas of the new Board Members, and we will re-assess our medium-term strategic goals in a new three-year strategy, to be published in late 2017.

2017 will therefore be a year of consolidation, to prepare ECPC to fulfil the new strategic mission that the new Board to define. The main objective of the 2017 Action Plan is therefore to confirm ECPC's leadership as the main voice of cancer patients in Europe, by strengthening the organisation and reinvigorating the connection between ECPC and its Membership.

At the same time, ECPC will refocus its policy priorities on the basis of the successes achieved in the period 2013-2016. The advocacy and campaigning work for 2017 will keep following the main commitments taken in 2016. However, in parallel with the definition of the new three-year strategy, ECPC will explore new policy fields, to keep up with the main ECPC mission.

## Increase capacity building initiatives

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 organisation 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 national policy.

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## Focus on key policy issues for cancer patients

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

In 2017, ECPC will focus on developing the main policy themes explored in 2016:

- inequalities in access to quality cancer care;
- innovation in oncology;
- survivorship and rehabilitation issues;
- cancer patients' participation 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 2017 is to confirm ECPC's commitments undertaken in 2016 and to keep following the main EU policy files for 2017.

## Developing and consolidating partnerships

Between 2013 and 2016, ECPC consolidated the relationship with several other health stakeholders, and build new bridges with new partners. Among others, the results from the Memorandum of Understanding ECPC signed with ESMO, OECl and CDDF will ripen in 2017, contributing to a compelling pack of joint initiatives that ECPC will undergo with its main partners.

The objective for 2017 is to further enlarge partnerships with the existing partners, and to identify new stakeholders with which establish similar formal partnerships.

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## Strengthening ECPC

### Increase dissemination capacity

Between 2013 and 2016 ECPC has re-established itself as the voice of cancer patients in Europe. Our outreach has increased exponentially since 2013, with the establishment of a new Board, the hiring of a Public Affairs Coordinator 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 our impact to internal and external stakeholder;
- increasing our 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 our partners in the capacity of ECPC to truly represent cancer patients' voice.

To sustain ECPC's growth and the rise of responsibility, we need to differentiate our 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.

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## How to read the ECPC Action Plan 2017

ECPC action plan outlines the main proposed activities for 2017. The activities are divided in:

- **Advocacy and campaigns** relate directly to ECPC mission to represent European cancer patients and to our capacity to raise awareness on key policy issues affecting cancer patients;
- **Collaborations** are projects and initiatives implemented in partnership with our key stakeholders. They pertain to our capacity to represent cancer patients 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 our Members with the necessary skills to conduct cancer policy advocacy, as well as with European added value in their daily fight against cancer. These are projects aiming at educating and empowering our members to add cancer policy advocacy to their activities and at providing them with new instruments to help cancer patients;
- **Research projects** allow us to be on the forefront of scientific developments on cancer, providing the patients perspective to the best EU research.

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

All our activities are clustered in chapters. For each activity or cluster of activities, ECPC prepared an accurate budget following the principle of [full cost recovery](#).

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## Calendar of main activities for 2017

- **January**
  - Launch of Value of Innovation at the European Cancer Congress
  - Launch of the ECPC-OECI Joint Declaration at the European Cancer Congress
  - Launch of the White Paper on Prostate Cancer
- **February**
  - World Cancer Day
  - Joint Action on Cancer Control (CanCon) final event in Malta
- **March**
  - Launch of the new Access section on the immuno-oncology portal
  - Launch of the new biomarkers webpage
- **April**
  - Immuno-oncology event at the European Parliament
- **May**
  - Bladder cancer awareness campaign
- **June**
  - Immune-oncology portal available in six languages
  - ECPC Annual Meeting
- **September**
  - Make Sense Head & Neck Cancer Campaign
  - Prostate Cancer Awareness Day
- **October**
  - Launch event for nutrition information materials
  - Launch of White Paper on the Condition of Cancer Patients' Carers
- **November**
  - Launch of the bladder cancer webpages
  - World Pancreatic Cancer Day
  - Biomarkers event at European Parliament

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## Advocacy and Campaigns

### Make Sense Campaign (ongoing, confirmed)

#### Rationale and objectives

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 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 2017 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 cancer patients and survivors.

Cervical cancer is the 3<sup>rd</sup> most common form of cancer among women worldwide<sup>1</sup>. HPV is responsible for most of the cervical cancer cases and is the causative agent of several other mucosal and skin diseases. Among the 100 HPV types, type 16 and 18 are responsible for 70% of cervical cancer cases, followed by 31, 33, 35, 45, 52 and 58<sup>2</sup>.

Over the last years, there has been a sharp decrease (68%) in HPV 16 and 18 infections before and after the vaccinations periods<sup>3</sup> in countries with HPV vaccination coverage of at least 50% for girls and young women.

Global cost-effectiveness analysis informed by country based evidence suggests that vaccinating pre-adolescent girls is usually cost-effective, particularly in resource constrained settings where alternative cervical cancer prevention and control measures often have limited coverage<sup>4,5</sup>. Meanwhile, some studies in high-income settings have reported that vaccinating adolescent boys for cervical cancer prevention might potentially be cost-effective, if vaccine coverage in girls is high<sup>6,7</sup>.

#### Implementation

Event in the European Parliament discussing head and neck cancers

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<sup>1</sup> [http://globocan.iarc.fr/Pages/fact\\_sheets\\_population.aspx](http://globocan.iarc.fr/Pages/fact_sheets_population.aspx)

<sup>2</sup> Smith JS, Lindsay L, Hoots B, Keys J, Franceschi S, Winer R, et al. Human papillomavirus type distribution in invasive cervical cancer and high-grade cervical lesions: a meta-analysis update. *Int J Cancer* 2007;121(3):621–32

<sup>3</sup> Drolet M, Benard E, Boily MC, et al. Population-level impact and herd effects following human papillomavirus vaccination programmes: A systematic review and meta-analysis. *Lancet Infect Dis* 15:565-580, 2015

<sup>4</sup> Kim SY, Sweet S, Chang J, Goldie SJ. Comparative evaluation of the potential impact of rotavirus versus HPV vaccination in GAVI-eligible countries: a preliminary analysis focused on the relative disease burden. *BMC Infect Dis*, 2011;11:174.

<sup>5</sup> Jit M, Brisson M, Portnoy A, Hutubessy R. Cost-effectiveness of female human papillomavirus vaccination in 179 countries: a PRIME modelling study. *Lancet Global Health*, 2014 ; 2(7) : e406.

<sup>6</sup> Chesson HW, Ekwueme DU, Saraiya M, Dunne EF, Markowitz LE. The cost-effectiveness of male HPV vaccination in the United States. *Vaccine*, 2011 Oct 26;29(46):8443- 50.doi: 10.1016/j.vaccine.2011.07.096.

<sup>7</sup> Burger EA, Sy S, Nygård M, Kristiansen IS, Kim JJ. Prevention of HPV-related cancers in Norway: cost-effectiveness of expanding the HPV vaccination program to include pre-adolescent boys. *PLoS One*, 2014;9(3):e89974

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Possible topics:

- **Life after diagnosis and post-treatment care.** Head and neck cancer not only alters the appearance and the personal functions of patients, but it forces patients to reconsider their outlook on life, their role within a family, their professional life and their future. Moreover, even for a survivor, the ongoing effects of the disease have overpowering psychological and physical consequences.
- **The need of uniform vaccination programs across all EU member states**  
Despite recommendations made by WHO to introduce vaccination programs, only 8 EU countries (e.g. Belgium, France, Germany, Greece, Italy, Luxembourg, the Netherlands and United Kingdom) have implemented such programs (*Bailey, H. et al. American Society of Clinical Oncology Statement: Human Papillomavirus Vaccination for Cancer Prevention. Journal of Clinical Oncology, Vol. 34, Nr. 15, 2016*). **Given the high burden of cervical cancer, high efficacy and relative cost-effectiveness of the two vaccines it makes economic sense to take serious measures to reduce the epidemic.**
- **Reimbursement of the vaccines**  
Variation in the funding and implementation scheme matching the economic and social realities of each country have been observed. (*Bailey, H. et al. American Society of Clinical Oncology Statement: Human Papillomavirus Vaccination for Cancer Prevention. Journal of Clinical Oncology, Vol. 34, Nr. 15, 2016*). For instance, in the United Kingdom the vaccination is offered free of charge while in France up to 35% of the costs are covered by individuals. Given that the health sector is underfunded in Eastern Europe additional measures needs to be in place to make vaccination sustainable in the long-run. Furthermore, vaccination at an early stage together with other vaccines may increase the vaccine uptake, which continues to be low.
- **The introduction of vaccines should use an integrated approach.**  
This strategy should include education about reducing behaviours that increase the risk of acquiring HPV infection, training of health workers and information to women about screening, diagnosis and treatment of precancerous lesions and cancer. For the prevention of cervical cancer, the WHO-recommended target age group for HPV vaccination is girls aged 9–13 years, prior to becoming sexually active. This is because HPV vaccines are most efficacious in those who have not previously been exposed to the virus. HPV vaccination of males is not recommended as a priority, especially in resource-constrained settings, as the available evidence indicates that the first priority should be for cervical cancer reduction by timely vaccination of young females and high coverage with each dose.
- Overpassing cultural differences/ mentalities in regards to HPV vaccination (an integrated approach).
- **The Economic Value of HPV Vaccination – Head, neck and cervix cancer**  
<http://www.economist.com/blogs/economist-explains/2016/03/economist-explains-24>  
<http://www.jmahp.net/index.php/jmahp/article/view/29414>.

Timeframe

Event to take place in September during MAKE SENSE week, preparation to start in June 2017.

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## Bladder Cancer survey, campaign, webpages (ongoing, confirmed)

### Rationale and objectives

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 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.

### Objectives

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

### Implementation

This proposal outlines some ideas in view of developing a sustainable and long term basis for advocacy to promote the voice of bladder cancer patients.

To ensure a sustainable advocacy platform, a stepped approach is suggested.

#### ***Step 1: Define the structure, membership and proceedings of the group***

Fight Bladder Cancer UK, under the stewardship of ECPC Board member Andrew Winterbottom, will lead the development of this project.

The first step of this advocacy group hosted by the ECPC would be to determine its structure, members of the group and proceedings. The group should also assess its man power capacity and level of funding to implement advocacy activities.

As a first step, the lead of the subgroup will identify individuals and patient associations that are already members of the ECPC, but also outside of this circle. Some thought should be given at inviting physicians/associations' representatives and academia (all the experts contributing to the draft of the 2016 Paper are willing to continue to be involved, also at national level, in the countries where they activate). The advantage would be that these members could support the work of the group with their technical expertise. This would also ensure a broader audience for the group. The group will also consider the development of partnerships with other international bladder cancer patient advocacy groups in order to launch a Global Patient Voice for Bladder Cancer.

#### ***Step 2: Agree on common objectives, vision for the group, main messages and policy asks and agree on immediate next steps***

Once the membership has been defined, the group will meet to develop a common set of values and a common vision for the group. It will be important to manage the expectations of the group as well as to identify clear deliverables.

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Once that the initiatives have been identified, different activities and actions can be considered. For example, it could be considered to obtain a direct reference in a document being discussed in the European Parliament.

The advocacy plan should also be supported at national level.

Some activities that could be implemented by the group:

- Patient experience survey
- Awareness campaign
- Webpages to support bladder cancer patients and policy makers

### ***Patient experience survey***

To complement the advocacy work of the group on different European initiatives, the group could consider conducting a Pan-European patient experience survey

#### Survey target

The survey will aim to contain responses from at least one hundred bladder cancer patients and bladder cancer survivors. ECPC has already identified bladder cancer patients and survivors in Romania, Greece, UK, Italy, Austria. The survey will be made available to all bladder patients in Europe.

#### Survey scope: diagnosis and patient journey

- What type of doctor diagnosed you with bladder cancer?
- Did you see a family doctor before you saw a specialist?
- Did you see a urologist before you saw an oncologist?
- What were your first symptoms of bladder cancer?
- What tests did your doctor use to diagnose you with bladder cancer?
- How long did you have to wait for your test results to come back?
- What questions do you wish you had asked your doctor when you were first diagnosed with bladder cancer?
- What factors made the treatments easier?
  - Family support
  - Peer support
  - Education

### ***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 we stand together for those currently undergoing treatment and everyone who is affected by bladder cancer.

Bubbles for Bladder Cancer is an annual event for people across the world affected by bladder cancer.

ECPC will host a Social Media Thunderclap in May 2017 to promote Bladder Cancer Awareness Month. 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 together.

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## **Webpages**

Building upon the activities listed above, two additional webpages will be created.

### 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?

## Deliverables

- European Bladder Cancer Advocacy Group statement on values and vision
- Bladder cancer patient experience survey
- Bladder cancer patient experience survey report
- Bladder cancer policy webpage
- Bladder cancer patient education webpage
- Awareness campaign

## Timeframe

January 2017: Production of survey

February 2017: Launch of survey

April 2017: Analysis of survey and report

May 2017: Bladder Cancer Awareness Month

August 2017: Stakeholder discussions for webpages

September 2017: Draft of webpages

October 2017: Approval of webpages

November 2017: Launch of webpages

December 2017: Promotional campaign

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## Nutrition (ongoing, confirmed)

### Rationale and objectives

Nutrition is a crucial component of cancer treatment and rehabilitation as it helps the organism to better cope with the illness. However, given the focus on the cancer and its cure, nutrition is often neglected, leaving the patient and 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 nutrition and its importance on the treatment and life of cancer patients. The results were presented during the ECPC AGM 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.

Learning from our experience, in 2016 we continued our 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 cancer patients 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 will develop a scientific paper on nutrition, based on empirical data, to be published in a peer-reviewed journal.

The paper can provide a solid basis for the development of patient friendly information material on nutrition. Indeed, cancer patients need to have the tools to ask more from their clinicians, who unfortunately demonstrate to neglect the nutritional needs of cancer patients.

Additionally, ECPC will also produce a charter of rights of cancer patient for appropriate and early nutritional support. This charter will be a key advocacy tool for patient organisations at national level.

### Implementation

Following the drafting of the paper and in order to fill in the information gap, ECPC will produce the several resources (see Deliverables) aimed at providing additional support to patients and doctors with regards to nutrition.

All documents will be revised by a team of expert patients that ECPC will identify and contact and translated with the help of ECPC Members at national level.

- ECPC will involve the oncologists the initiative. One of the main issues highlighted in the survey is that oncologists/doctors neglect nutrition. ECPC will discuss bringing ESMO on board asking them to support this project
- Finally, ECPC will promote the project and the materials during an event in Brussels, involving key stakeholders.

### Deliverables

- Scientific paper presenting the result of ECPC-run surveys
- An infographic that highlights the issues with regards to lack of information on nutrition.
- A charter of rights of cancer patients with regards to nutrition
- Cachexia-focused information, which will explain the nature, causes and implications of cachexia in cancer patients, and how to proactively solve the problem.
- A glossary with nutrition terms (what is a supplement, what is BMI, what is parenteral nutrition, etc., to be discussed with the experts)

- 
- A leaflet with “Key questions to ask your oncologist on your diet” that will be disseminated in hospitals and GP offices
  - Policy recommendations to integrate nutrition into disease management

#### Timeframe

- October 2016– February 2017: Writing of the first draft of the scientific paper
- January 2017 – May 2017: Production of information materials
- May 2017 – June 2017: Translation of materials
- June 2017: Session on multi-disciplinary care at ECPC AGM
- October 2017: Launch event introducing policy recommendations, paper and materials

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## White Paper Cancer Patients' Carers (new, confirmed)

### Rationale and objectives

The incidence of cancer is on the rise: every year, more than 3.25 million Europeans are diagnosed with cancer, and overall, more than 10 million live with the disease today. With this increasing burden, comes also an increase in the number of carers who are currently helping cancer patients through their journey. Relatives and friends sustain patients not only with their passion and emotions, but also with time and resources. We know, for example, that more than 60% of the total financial burden of cancer weights on patients and their relatives, and a big portion of these costs are out-of-pocket payments and loss of income, often sustained by the relatives/friends of the patients.

For this reason, ECPC wants to raise awareness on the difficulties and challenges that carers of cancer patients face every day.

### Implementation

The broader needs and rights of carers have been explored and defended by other organisations in the past, most notably EUROCAREERS. However, the specific needs and challenges of cancer patients' carers remain unknown to the wider public and, most importantly, to the European and national policymakers.

Based on the direct experience of ECPC Members and Board, we will gather EU and national experts on social care issues in cancer to better define the issues that carers face in supporting cancer patients specifically. The objective is to produce the first White Paper on the Condition of Cancer Patients' Carers.

For the paper to be successful it has to include all stakeholders involved and, most importantly, receive direct feedback from our Membership. ECPC will therefore invite top European and national experts in economics, psychologist with experience in cancer care, professional carers and rehabilitators, lawyers and medical professionals to collect the best professional and knowledge base for the paper.

Patients' input will be guaranteed by the direct involvement of ECPC Members. The ECPC Secretariat will launch a call for expression of interest to invite Members to participate to the drafting of the document. Furthermore, ECPC will also invite other key patients and carers associations (for example EUROCAREERS) to learn from their work and previous experiences.

Furthermore, ECPC will identify Members of the European Parliament willing to take up the fight to protect the rights of cancer patients' carers. The championing Members of the European Parliament will be involved in the drafting and will host the launch of the paper. They will be protagonists in disseminating the paper and calling the European Union's action.

Finally, ECPC will also invite the European Commission and the Council of the European Union to participate to the paper, in order to ensure that their perspectives and information will be considered. The direct link that ECPC has with several Commission's DG will facilitate the involvement of the relevant EU services to provide input to the paper.

A Core Writing Group will be created, composed of all ECPC Members, Members of the European Parliament, experts, EU institutions' representatives and other patients/carers organisations. The Core Writing Group will be supported by the ECPC Secretariat (Director and Public Affairs Coordinator).

ECPC will enjoy the experience gathered with the very successful production and publication of the [White Paper on Bladder Cancer](#) (2016), the Immuno-Oncology Policy Action Framework (2015), the ECPC Policy Strategy "Challenging a Europe of Disparities in Cancer (2015).

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## Potential sub-themes or case studies

- Difficult-to-treat cancers
- Metastatic cancers
- Blood cancers
- The role of gender in caring for cancer patients

## Deliverables

- White Paper on the Condition of Cancer Patients' Carers;
- Launch event for the Paper at the European Parliament, Brussels (Autumn 2017);
- Establishment and management of the Paper's Core Writing Group.

## Timeframe

- January – March 2017: call for interest to ECPC Members, to participate to the paper Core Writing Group;
- January – March 2017: identification of EU and national experts to be involved in the paper, including:
  - Members of the European Parliament;
  - Representatives from the European Commission and Council of the EU;
  - Economists;
  - Psychologists, sociologists, oncologists;
  - Professional carers – rehabilitation specialists;
  - Lawyers;
  - Other patients/carers organisations.
- March 2017: Kick off meeting of the Core Writing Group
  - Definition of the paper's objectives;
  - Input on the paper's structure and content from all participants;
- March – June 2017: writing of the first draft;
- June 2017 (ECPC AGM):
  - discussion of the draft findings at a dedicated session during the AGM;
  - face-to-face meeting of the Core Writing Group after the AGM Session, to discuss the outcome of the debate;
- June – August 2017: finalization of the paper with input from the ECPC AGM;
- October 2017: presentation of the paper at the European Parliament.

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## White Paper on Prostate Cancer (new, confirmed)

### Rationale and objectives

ECPC will connect with the International Society of Urology (SIU), the European Association of Urology (EAU) and Europa Uomo to produce a large European initiative on prostate cancer. This initiative will involve a Round Table on Prostate Cancer, a White Paper, and promotion of European Prostate Awareness Day.

### Implementation

#### White paper

Following the blueprint of the very successful ECPC White Paper on Bladder Cancer, ECPC and its partners will develop a white paper which will include a section calling for action at EU level. ECPC will contribute sections on survivorship (rehabilitation, late effect, tertiary prevention) and the social aspects (disability and return to work).

The White Paper will result from the consensus among the core writing group, coordinated by the EAU, and in which ECPC will be a key member.

The White Paper will then be finalised in a printed and online format for further dissemination.

#### European Prostate Cancer Awareness Day

European Prostate Cancer Awareness Day aims to raise awareness, understanding and knowledge of the management of prostate diseases in general and prostate cancer in particular. As part of European Prostate Cancer Awareness Day, ECPC will promote the symptoms of prostate cancer and how to improve care and empower people living with this disease.

### Deliverables

- White paper on Prostate Cancer
- European Prostate Awareness Day Campaign

### Timeframe

- 24 January 2017: Launch of White Paper on Prostate Cancer
- September/October 2017: European Prostate Cancer Awareness Day

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## Legal Network for Cancer Patients (new, confirmed)

### Rationale and objectives

ECPC aims at establishing a Pan-European network of volunteer legal practitioners that will reinforce the advocacy work of the ECPC and cancer patients with legal instruments.

What we are looking for: recruit a solid base of legal practitioners that aim to share their legal competences to the benefit of cancer patients on a volunteer basis. ECPC will create an online platform where lawyers across Europe can exchange information and provide legal advice.

In August 2016 ECPC therefore launched a call for expression of interest to all its Members to join the newly founded Legal Network for Cancer Patients (LNCP)

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

### Core activities

#### ***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 LNCP will act as a „legal watchdog“ in cases of doubtful transposition. ECPC Board might, at the request of the LNCP, adopt a position and make a statement on the issue at stake.

#### ***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 Cimpoeru, who won 17 lawsuits against the Romanian government and now a number of 165 cancer patients are receiving medical treatment for free. This is a real example that we can build a national lawsuit based only on the EU rules. Starting from this, the LNCP could provide legal assistance for national NGOs.

#### ***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.

#### ***An Online Health Library***

Establish an online library with legal resources on health from various Member States. The LNCP members would translate into English the relevant extracts from national laws and download them on the ECPC website.

#### ***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 LNCP lawyers will support ECPC advocacy work with legal arguments to reinforce some of its messages. LNCP will become a think tank generating ideas for the ECPC. For this purpose, the LNCP will organize working groups for studying different legal matters.

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### Specific legal initiatives

The LNCP will support the ECPC policy by providing ECPC with insights and understanding of key legal files related to relevant European and national issues.

Furthermore, upon creation of the LNCP, its Members will be able to create an own action plan of the LNCP, containing specific legal initiatives that the Network will deem necessary and useful to fulfil the mission of the network itself.

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## Immuno-Oncology (ongoing, confirmed)

### Rationale and objectives

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

The very positive feedback received from our Membership included some comments on the possible development for the future of the IOP. Our Members have asked for more clear and updated information on how to access cancer immunotherapies. ECPC intends to answer to this need in 2017 by creating a new Access section on the IOP website.

Since 2015, ECPC pressed the Joint Action on Cancer Control (CanCon) to take a strong stance on the issue of inequalities in cancer, which are also deeply affected by the availability of innovative lifesaving medicines like immuno-oncology drugs. As a result, the CanCon project coordinator agreed to include a new deliverable of the Joint Action: a policy paper on social inequalities in cancer, which was deeply influenced by the ECPC "Challenging the Europe of Disparities in Cancer" and co-authored by ECPC. The paper, which will be launched at the CanCon final conference in Malta in February (event hosted by the Maltese Presidency), is a ground-breaking achievement for ECPC, as it provides key recommendations endorsed by all CanCon partners and health ministries participating, on how to fight inequalities in cancer care. It includes a whole chapter on the need by cancer patients to have faster and more equitable access to innovative medicines, including immuno-oncology.

In 2017 ECPC wants to promote the CanCon recommendations on how to boost equitable access to innovative medicines, including immuno-oncology, raising the European Institutions' awareness on the consensus achieved within patients, academics and national policymakers. To do so, ECPC will organise a dedicated event at the European Parliament to promote the actionable solutions and recommendations on access to innovative treatments of the CanCon paper, focusing specifically on immuno-oncology. The outcome of the event at the European Parliament will be reported and presented at the national level, via three sister events to be organised in partnership with ECPC Members.

#### 4.9.1 Background

The momentum set by the recent policy development at the EU level is ideal for launch of the ECPC-CanCon policy paper on social inequalities in cancer.

In October 2016, the European Commission launched a public consultation on strengthening the cooperation on Health Technology Assessment (HTA), a key component of the processes at European and national level to evaluate innovation in healthcare. ECPC welcomed the Commission's roadmap on HTA, which is in line with the amendments that ECPC promoted within the European Parliament to the regulation 726/2004 (functioning of EMA) and approved with an overwhelming majority by the ENVI Committee (February 2016) and later on by the European Parliament in plenary (March 2016). The public consultation demonstrates that the policy objective of ECPC in this regard has been received by the Commission: the consultation will give us a further chance to promote the concept that effective and meaningful innovation, like immuno-oncology, must reach the patients fast also via a more efficient and speedy HTA evaluation.

The value of immuno-oncology is also central in our work on the own initiative report on access to medicines, currently debated within the European Parliament. It provides a perfect chance to address the issues related to the existing regulatory pathways, at EU and national level, for the approval and

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reimbursement of innovative medicines. We are already working in close collaboration with the European Parliament to ensure that the report will provide actionable and practical solutions to the problem of how to guarantee fast and equitable access to new lifesaving medicines, while ensuring healthcare systems' financial sustainability.

The European momentum substantiating around the issue of access to immuno-oncology is further sustained by the ECPC "Value of Innovation in Oncology" paper (to be published in January 2017) which underlines the need to better involve cancer patients in the definition of meaningful innovation in oncology, and stresses the importance of systemic innovation, not only in relation to new medicines, but throughout the patients' journey.

#### 4.9.2 Implementation

Following the launch of the CanCon paper in February 2017, ECPC will organise an event at the European Parliament in April 2016 to raise awareness of the other EU institutions regarding the ground-breaking content of the policy paper.

The meeting will be prepared by a social media campaign on the ECPC channels to ensure that Brussels-based organisations and EU institutions are aware of the event.

ECPC will ask several MEPs with a proven record of fruitful engagement in cancer to host the event, for example:

- Cristian-Silviu Busoi, EPP, Romania;
- Lieve Wierinck ALDE, Belgium;
- Elisabetta Gardini, EPP, Italy;
- Eva Kaili, S&D, Greece.

Furthermore, the event will feature a keynote presentation from one of the main authors of the policy paper, like:

- Prof Michel Coleman, Professor of Epidemiology and Vital Statistics, London School of Hygiene and Tropical Medicine;
- Prof Mark Lawler, Chair in Translational Cancer Genomics, Centre for Cancer Research and Cell Biology, Queen's University Belfast

We would also foresee a brief comment from the Joint Action Project Coordinator team, in the person of:

- Dr Tit Albreht, Institute of Public Health, Slovenia;
- Dr Giovanni Nicoletti, Ministry of Health, Italy.

Finally, we would appreciate the perspective of industry in relation to the paper, which could come from:

- Francois Bouvy, Director Market Access, EFPIA.

The event will be followed by a report, produced by ECPC, and including the main messages of the conference. The report will be disseminated across the ECPC Members to all EU Member States, therefore pushing for the implementation of the CanCon recommendations, with a clear focus and practical objective on the obstacles related to immuno-oncology.

Furthermore, ECPC will organise 3 sister events at the national level, in collaboration with our Members, to bring the outcome of the CanCon paper and the ECPC position on immuno-oncology to the attention of national policymakers. Each event will feature a keynote speech from ECPC, presenting the outcome of the European Parliament event and the relevance of the chapter on innovative medicines included in the

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CanCon policy paper on inequalities. ECPC Members, local sponsors' representatives and national policymakers will be invited to comment on the topics presented by ECPC.

#### Access

The "Access" section of the IOP website ([iop.ecpc.org](http://iop.ecpc.org)) will provide updated information on availability and reimbursement of immuno-oncology medicines, independently collected by ECPC.

Similarly, to other industry-sponsored initiatives (for example the European Atlas of Access to Melanoma Treatment) ECPC will organise into one website existing information on access and reimbursement of immuno-oncology treatments pooled from publicly available sources, such as:

- List of EMA approved immuno-oncology treatments, including a direct link to the related European public assessment report published on the [EMA website](#);
- Information from public sources, such as:
  - Websites of the competent authorities mentioned on the [EMA website](#);
  - Websites of national and local authorities competent for reimbursement, as listed by the [IMI project PROTECT](#);
  - [Health Systems and Policy Monitor \(HSPM\)](#) of the WHO European Observatory on Health Systems and Policies;

In case no information would be available from the sources listed above or other public sources, ECPC will directly survey its Members (national level).

Furthermore, the Access section will include a "News" subsection, which will mirror key news on cancer immunotherapies, in particular:

- A database of articles on cancer immunotherapies, expanding on the existing bibliography for the IOP Modules;
- A selection of news on the development of cancer immunotherapies published by independent news outlets-editors;

The News sub-section will be populated by mirroring article coming from independent news outlets, such as:

- The Lancet Oncology
- British Medical Journal
- European Cancer Journal
- Annals of Oncology
- eCancer

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#### 4.9.1 Deliverables

- New Access section on the IOP website
- Monitoring for 1 year of all relevant news related to cancer immunotherapies
- Communication campaign advertising the event and the specific chapter on the CanCon policy paper on inequalities pertaining to immuno-oncology
- Event at the European Parliament
- Report of the event, published on the ECPC website and disseminated to ECPC Members
- Three events at national level (countries to be determined) to report the conclusions of the European Parliament event
- Final report about the initiative

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## Timeframe

- February 2017: Design of Access section on the website
- March 2017: Kick-off for the communication campaign of the event
- April 2017: Event at the European Parliament
- April 2017: Collection of the first round of information and publication on website
- May 2017: Report of the event published on the ECPC website
- June 2017: Monitoring of relevant news and updating Access section
- October 2017: organisation and implementation of the three national events
- December 2017: report on the whole initiative.

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## Biomarker Campaign (new, confirmed)

### Rationale and objectives

Cancer biomarkers are proteins or other biological substances or processes that give information about the presence and activity of cancer in the body. They are usually detected in blood or urine, and 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 150 cancer patients and survivors, and found that biomarkers are still largely unknown by cancer patients and are insufficiently used by physicians. Lack of reimbursement for biomarker testing in many European countries creates an obstacle for improving cancer patients' clinical outcomes.

In 2017, ECPC will begin the production of 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 discussion with experts in the field of biomarkers.

### Objectives:

- To promote the importance of biomarkers to cancer patients in Europe
- To raise awareness of the important role that biomarkers play in cancer treatment
- To create educational resources about biomarkers for cancer patients
- To raise public awareness and understanding of the importance of biomarker testing
- To educate policy makers of the importance of biomarker testing

### Event in the European Parliament on Biomarkers

The event will be moderated by ECPC and will bring together stakeholders and policymakers. This would attract an expert audience from the Commission, member states representatives, patient advocacy groups, health economists, academia, members of the European Parliament and payers. An after the event report that should be distributed among key stakeholders and participants would be the basis of further advocacy activities.

Suggested structure: *discussion with experts in the field on what needs to be done to make personalized medicine in cancer a reality using biomarkers as an example.*

Timing: the event could be organised after the adoption of the Council conclusions in October/November. The debate in this case would be a follow-up to the personalized medicines debate and a platform to discuss further steps and policy implications.

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## Draft Agenda of Event

- Welcome from Member of the European Parliament
- Presentation of biomarkers webpage and policy recommendations
- Personal testimony from cancer patient
- Roundtable discussion:
  - Representative, European Alliance for Personalised Medicine
  - Representative, Bowel Cancer UK
  - Gemma Binefa, author of “Colorectal Cancer: From Prevention to Personalized Medicine.”
  - Representative, DG SANTÉ
- Closing remarks

## Biomarker webpage and infographic

In 2016, ECPC members responded to a survey about cancer biomarkers in their country. Building upon the results from this survey, a webpage will be created, with patient information and policy recommendations.

The webpage will answer the following questions:

- What is a biomarker?
- What types of cancers have established biomarkers? (e.g. Breast, colorectal, gastric, GIST, blood, lung, melanoma, pancreas, liver, ovary)
- When are biomarkers beneficial? (e.g. risk, diagnosis, prognosis, recurrence, etc.)
- Where in Europe are biomarkers reimbursed?
- What are the policy recommendations? (e.g. education, access, adapting regulatory framework)

## Deliverables

- Awareness-raising event on the importance of biomarkers, to be organised at the European Parliament
- Biomarker webpage and infographic

## Timeframe

- January 2017: identification of the biomarkers webpage content
- March 2017: launch of the biomarkers webpage and infographic
- June – September 2017: identification of the event participants and speakers
- October – November 2017: event at European Parliament

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## Value of Innovation in Oncology (ongoing, confirmed)

### Rationale and objectives

Innovative technologies and services can save, improve and extend the lives of millions of people diagnosed with cancer each year in Europe. Innovation should aim to 1) Promote patient-centred, multidisciplinary care that makes optimal use of all indicated therapeutic modalities and enabling technologies; 2) Improve upon existing care (measured by quality of life as well as survival); and 3) Benefit everyone. Ensuring that innovations are accessible in a timely and affordable manner to all patients is a challenge.

“Value of Innovation in Oncology” presents the position of the European Cancer Patient Coalition (ECPC) on innovation in oncology and offers recommendations to help reduce variations in access to innovation and to involve patients in decision-making.

The paper will be presented during a dedicated press conference at the European Cancer Congress in Amsterdam (January 2017).

### Implementation

Based on the “Challenging the Europe of Disparities in Cancer” paper (ECCO 2015), ECPC and the Brussels-based consultancy Interel collaborated on a literature and policy review on issues of access to innovation in oncology, consulting with ECPC member organisations during the ECPC Annual General Meeting. The drafting of the document started in 2016 and funding for the writing has been secured.

ECPC submitted an abstract to ECCO to feature the document in the main poster session.

Furthermore, ECPC will organise a dedicated press conference during the ECCO congress (within the venue of the congress) to launch the paper to the media.

### Deliverables

- Press conference for the launch of the position paper “Value of innovation in oncology”.

### Timeframe

- January 2014 (within the ECCO2017): press conference.

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## World Cancer Day (ongoing, confirmed)

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

ECPC will also use World Cancer Day to promote the ECPC Legal Network for Cancer Patients and the Value of Innovation.

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## The CanCon Guide (ongoing, confirmed)

### Rationale and objectives

The Joint Action on Cancer Control – CanCon will end in February 2017, after three years of ground-breaking work to harmonise the way we fight cancer. The final deliverable of the Joint Action, the Guide on Quality Improvement in Comprehensive Cancer Control will be presented in February 2017 at a dedicated meeting in Malta, hosted by the Maltese Presidency of the European Union.

From that moment on, ECPC will work to disseminate the Guide and push Member States to implement the recommendations of the Guide.

### Implementation

ECPC has contributed, as co-author, to several chapters of the Guide, in particular:

- Chapter on the Member State Platform, via the direct drafting of 2 policy papers:
  - Inequalities in cancer care
  - Disinvestment
- Chapter on Survivorship and Rehabilitation;
- Chapter on Comprehensive Cancer Control.

In light of our engagement, we will disseminate the Guide, through:

- ECPC social media (Facebook and Twitter);
- ECPC website, via a dedicated section;
- Public engagement with other stakeholders in occasion of meetings and congresses.

Furthermore, ECPC will cover and report on the outcome of the Guide launch meeting in Malta.

### Deliverables

- ECPC participation to the CanCon Guide launch event in Malta
- Communication and dissemination campaign towards ECPC Members and stakeholders

### Timeframe

- February 2017: Guide launch event in Malta;
- February – December 2017: dissemination of the Guide's recommendations on ECPC social media;
- February 2017: update of the CanCon section on the ECPC website.

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## Photo exhibition: Cancer marks us for life (new, confirmed)

### Rationale and objectives

"Cancer marks us for life" is a meaningful phrase that is repeated continuously by all patients and their families who came across this disease. Once installed, the patient witnesses two stages: 'before' and 'after' the battle. Cancer is absolutely ruthless and generates mixed, very often extreme feelings. Fear and hopelessness, but also passion and desire for life. In order to share these strong emotions and difficult experience, 12 patients and relatives got their bodies painted with powerful drawings that show everything that makes them laugh and cry. Whatever they dream of. Anything that gives them a strong will to live on.

This project aims to show the stories of brave hearts who, no matter how tough the battle is, want to enjoy their lives to the fullest. It also underlines that cancer disease always leaves its mark, thus, special attention should be paid to specific needs and condition of cancer patients, survivors and their relatives.



### Implementation

This initiative is led by GEPAC, an ECPC member organisation, and it involves 12 patients and relatives. During closed sessions run by psycho-oncologists, patients and relatives engaged in the project talked about their worries and fears, desires and passions. After having interpreted all gathered information, a group of body painting artists designed drawings that would tell powerful stories of brave people.



ECPC will organise in June 2017 a digital photo exhibition during the ECPC Annual Meeting exhibiting the best photos in a special way.

<http://gepac.es/diadelosurviviente2016/>

<https://gepac.es/diadelosurviviente2015/>

### Deliverables

- Digital photo exhibition during ECPC Annual Meeting

### Timeframe

- June 2017: Digital photo exhibition during ECPC Annual Meeting

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## **Pancreatic Cancer (ongoing, confirmed)**

World Pancreatic Cancer Day (ongoing)

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
- Promoting World Cancer Day in the News section of the ECPC website

Deliverables

- World Pancreatic Cancer Day campaign;
- A report of the workshop and World Pancreatic Cancer Day campaign.

Timeframe

- November 2017: World Pancreatic Cancer Day;
- December 2017: publication of the World Pancreatic Cancer Day report.

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## Biobanking – a resource for patients (new, pending)

### Rational and objectives

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 build on the success of the GDPR lobbying to make sure that all European Cancer Patients can profit of the advantages benefits of contributing to European biobanks.

Do European patients know about the role of biobanks? Are we fully exploiting the potential of biobanks? But most importantly, what can patients benefit from once they donate samples and data to biobanks? In 2017, ECPC and BBMRI-ERIC will work together to provide an answer to these burning questions.

### 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.

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## **ECPC – BBMRI-ERIC patients’ portal and journal**

These specific initiative covers the first area of intervention identified, *Patient education and awareness*.

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 biobanking is 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. ([click here](#))

The content of the website will be produced by the ECPC-BBMRI-ERIC working group, in collaboration with a medical writer. The website will also be translated in three languages (French, German, Italian).

Journal

To increase the patients’ understanding of the complex and crucial role biobanks play in modern cancer research and treatment, ECPC and BBMRI-ERIC recognised the need to increase the patients’ general awareness on the forefront developments of cancer research.

For this reason, ECPC and BBMRI-ERIC will publish an online journal dedicated to the translation in patient-friendly languages of the principal achievements in cancer research. The journal, published every 6 months, will include key European and international studies, focusing on all aspect of treatment (drugs development, surgery, radiotherapy, etc....). The ECPC – BBMRI-ERIC working group will be responsible to draw the editorial line and to identify the contributors to the journal. Each issue of the journal will be checked by the ECPC Scientific Committee and by the relevant BBMRI-ERIC bodies. Each issue will be translated in three languages (French, German and Italian) and published online on the ECPC website and on the ECPC-BBMRI-ERIC portal.

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### ***Building national partnerships – face to face trainings***

Patients awareness and education is the pre-requisite for fruitful collaboration between ECPC Members and BBMRI-ERIC national nodes. The face-to-face trainings will aim at building a trustworthy relationship between the ECPC Members and BBMRI-ERIC national nodes, in order to create national solutions to increase the role of patients in biobanking.

The trainings target local patients and patients' advocates, but it is also open to healthcare professionals interested in knowing more about biobanking.

ECPC and BBMRI-ERIC will facilitate the organisation of three trainings in Italy, France and one other key country. Each training will have a duration of 1.5 days (12 h) and will be divided into 2 main sections:

- **Biobanking 2.0:** the participants will be asked to study and review the Portal and get acquainted with the basic concepts related to biobanking. At the face-to-face training, the organisers will go in depth with the topics, presenting more accurate and complex information about biobanking, therefore further enriching patients and building trust on biobanks. This section will be common to all three face-to-face training and will be produced by the working group (8 h);
- **National issues:** the second half of the training will be devoted to national and local issues. The participants will be asked beforehand to provide questions and issues that the organisers will address during this session. More interactive and collaborative, this session can include simulations of how a biobank works, visits to biobanking facilities and any other activity that the local organisers feel necessary to increase understanding of biobanking.

The ECPC- BBMRI-ERIC working group will identify a project coordinator for each of the three workshops, who will be responsible to adapt and translate the programme of the training for the local participants.

### ***European biobanking informed consent form model***

In the framework of the work of the BBMRI-ERIC Stakeholder forum (in which ECPC is a Member), we will cooperate to produce a European model for a new informed consent form model, to be used as a reference by all BBMRI-ERIC nodes.

The key principles of the new informed consent form will

- **Create truly informed patients:** the consent form should provide truly patient-friendly information. Based on the experience of the Portal content, ECPC and BBMRI-ERIC can work on a novel approach, involving patients in the drafting of the model informed consent;
- Fulfil the requirements of new General Data Protection Regulation;
- **Harmonise the collection of samples and consent across countries:** even with a new Pan-European regulation on data protection, Member States are left with much room for interpretation. In biobanking, this can lead to increased hurdles to share and aggregate data at the EU level, with dire consequences on research. The new informed consent form model will facilitate the harmonious and coherent collection of data and samples, therefore streamlining the sharing and ensuring patients' safety.

The workflow on the new informed consent form model will be an integral part of the **Code of Conduct on Biobanking**, that BBMRI-ERIC and its Stakeholder forum are already working upon.

Once the new informed consent form model will be developed, ECPC and BBMRI-ERIC will disseminate the result via a launch event at the European Parliament in Brussels, to increase policymakers' awareness on the achievements of our partnerships and to ensure that the informed consent model will be implemented across Europe.

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## 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;
- A bi-annual online scientific journal for cancer patients, which will translate in laymen terms the most important cancer research achievements;
- Three face-to-face trainings organised by expert patients/advocates and professionals in the field of biobanking, targeted at national and local patients' organisations;
- A model for a new informed consent form to donate samples to biobanks;
- An event at the European Parliament to raise awareness on the ECPC/BBMRI-ERIC initiatives and promote the uptake of the informed consent model.

## Timeframe

### Portal and training

- Month 0: Funding secured for project
- Month 1: establishment of the ECPC -BBMRI-ERIC working group;
- Month 5:
  - production of the content for the Portal;
  - production of the website;
- Month 6: launch of the Portal;
- Month 7:
  - definition of the programme of the face-to-face trainings;
  - identification of the training project coordinators (one per country);
- Month 12: implementation of the trainings (in three different countries).

### Informed consent and policy

- Month 0: Funding secured for project
- Month 5:
  - Discussion within the BBMRI-ERIC Stakeholder Forum of the new informed consent;
  - Agreement on the key principles
  - Definition of the core writing group for the new informed consent form model
- Month 7: finalisation of the new informed consent form model;

Month 10: launch event at the European Parliament.

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## White Paper on mHealth (new, pending)

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### Rationale and objectives

In May 2016, ECPC and PatientView, the patient-oriented communication agency behind [MyHealthApps](#), demonstrated to the European Parliament and to all EU stakeholders that cancer patients are ready to play a protagonist role in the development of eHealth/mHealth policies.

In 2017, we want to bring the policy debate to the next level, by producing the first White Paper on mHealth in cancer, to provide guidance to the European Institutions and to our stakeholders on the development and implementation of mHealth strategies for people with cancer.

The intermediate evaluation of the European Commission's eHealth Action Plan 2012-2020 will provide the perfect framework to produce and promote the White Paper.

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### Implementation

To create added value to the work already done by ECPC and PatientView, we will identify and bring together experts, MEPs and patients representatives to work with us and review and endorse the White Paper, which will then become the single voice of the whole cancer patients' and oncology community on mHealth. The list of members of the reviewers group might include:

- ECPC Members active in the field of mHealth
- Healthcare professionals, with a particular focus for:
  - Nurses, in particular the project partners of the EU funded research project "eSMART"
  - Medical oncologists (ESMO)
  - Radiotherapist (ESTRO)
- Industry (MedTech);
- Developers.

ECPC and PatientView will analyse the most important policy documents and developments at the EU level in the field of mHealth, in particular:

- The report and the findings of the mHealth event co-organised by ECPC and PatientView will be the baseline for the development of the White Paper, in order to ensure the full exploitation of the results of the conference.
- Furthermore, ECPC and PatientView will analyse and evaluate the Code of Conduct on mHealth apps and the work of the European Commission's Working Group on mHealth apps assessment guidelines (ECPC is represented in both by its Vice President Kathi Apostolidis; PatientView by its Director of MyHealthApps Dee O'Sullivan). Understanding and evaluating both these initiatives will be a crucial step in producing a white paper which is both actual in the content and forward looking in its application.
- Finally, we will revise the European Commission's eHealth Action Plan 2012 – 2020, underlining the inconsistencies with the position and needs of cancer patients.

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Subsequently, ECPC and PatientView will put together a core writing team, responsible of producing the first draft of the White Paper. The draft will be then circulated among the group of experts previously identified, who will review the White Paper and provide input and ensure that the paper represents the broader oncology and cancer patients' community. The White Paper will include sections on past achievements and the way forward.

Finally, once the document will be finalised, ECPC and PatientView will present at a launch event at the European Parliament and/or during the European eHealth Week (to be organised in Malta in June).

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## Deliverables

- ECPC-PatientView group of experts and patients involved in mHealth (peer reviewers);
- White Paper on mHealth in cancer;
- Launch event of the White Paper.

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## Timeframe

- Month 0: Funding secured for project;
- Month 1: identification of the group of experts and patients to be involved;
- Month 3: first draft of the paper to be presented to the reviewers;
- Month 6: finalisation of the White Paper
- Month 8: launch of the White Paper
  - Option A: event at the European Parliament;
  - Option B: launch at the eHealth Week (June);
  - Option C: launch at the European Public Health Forum Gastein (September).

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## Cancer and work (new, pending)

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### Rationale and objectives

Cancer is a major social and public health problem in Europe. Each year, an estimated 3.2 million new cases of cancer are diagnosed with half of them of working age<sup>8</sup>. Breakthroughs in cancer treatments and technological advances in cancer care mean that cancer patients are living longer, with over 64% surviving for at least five years after their initial cancer diagnosis<sup>9</sup>. On average a cancer patient in the UK has a 46.2% chance of being alive ten years after diagnosis compared with 23.6% thirty years ago<sup>10</sup>.

The consequence of these long-term trends is that cancer survival rates are going up and the number of people affected by cancer is rising sharply. It is estimated that one in every 38 European citizens is a cancer survivor which is 2.6% of the total European population. As cancer is predominantly a disease of older age, the ageing of the population in developed countries means that the number of survivors is predicted to increase even more<sup>11</sup>.

Even though likelihood of survival from cancer is increasing, cancer survivors are experiencing a broad array of physical, emotional and cognitive problems which can severely impact their social and occupational integration. Disability and ill health are often associated with poverty, social exclusion and, most importantly in terms of the social determinants, lower employment rates<sup>12</sup>. There is good evidence that people with cancer often experience difficulties at remaining at work; our meta-analysis showed higher unemployment risk among cancer survivors than people without cancer<sup>13</sup>. The mechanisms behind the higher unemployment rate among cancer survivors is likely to be a higher disability rate, which varies greatly by type and stage of cancer, occupation and educational level, for example<sup>14</sup>.

It has been shown that cancer rehabilitation, especially if entered early, can be effective in helping a person with cancer obtain the best physical, social, psychological, and work-related functioning during and after cancer treatment<sup>15</sup>. However, the reality is that survivors don't always receive the support they need to cope with long-term problems of their illness. In particular, the availability of and access to specialist return-to-work services is severely scarce<sup>16</sup>. Clinicians and other stakeholders often lack of adequate time, skills and resources to adequately address individuals' needs resulting in many cancer survivors lacking support and advice on how to cope with the ongoing problems from their cancer and its

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<sup>8</sup> Ferlay J, Autier P, Boniol M, Heanue M, Colombet M, Boyle P. Estimates of the cancer incidence and mortality in Europe in 2006. *Ann Oncol* 2007;18(3):581-92.

<sup>9</sup> Osborn R, Demoncada A. Psychosocial Interventions for Depression, Anxiety and Quality of Life in Cancer Survivors: Meta-analyses. *Int'l Journal Psychiatry in Medicine*. 2006;36(1):13-34.

<sup>10</sup> Corner J. Addressing the Needs of Cancer Survivors: Issues and Challenges. *Pharmacoeconomics Outcomes Research*. 2008;8(5):443-51.

<sup>11</sup> Micheli A, Mugno E, Krogh V, Quinn MJ, Coleman M, Hakulinen T, Gatta G, Berrino F, Capocaccia R; EUROPREVAL Working Group. Cancer prevalence in European registry areas. *Ann Oncol* 2002;13(6):840-65.

<sup>12</sup> Jans LH, Kaye HS, Jones EC (2011). Getting Hired: Successfully Employed People with Disabilities Offer Advice on Disclosure, Interviewing, and Job Search. *Disabil Rehabil* Oct 10.

<sup>13</sup> de Boer AG, Taskila T, Ojajarvi A, van Dijk FJ, Verbeek JH: Cancer survivors and unemployment: a meta-analysis and meta-regression. *Jama* 2009, 301(7):753-62.

<sup>14</sup> Taskila T, Lindbohm M-L. Factors affecting cancer survivors' employment and work ability, *Acta Oncologica* 2007; 46(4): 446-51.

<sup>15</sup> Mewes JC, Steuten LM, Ijzerman MJ, van Harten WH. Effectiveness of multidimensional cancer survivor rehabilitation and cost-effectiveness of cancer rehabilitation in general: a systematic review. *Oncologist*. 2012;17(12):1581-93. doi: 10.1634/theoncologist.2012-0151. Epub 2012 Sep 14.

<sup>16</sup> Macmillan Cancer Support: Making the shift –Providing Specialist Work Support to People with Cancer. March 2013.

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treatment leaving many patients feeling abandoned and isolated from society, putting them at risk of health and social problems.

In sum, there is increasing need to develop effective policies and practices in order to support cancer survivors, their families, employers and health care providers to enable survivors to fully participate fully in society.

ECPC wishes to highlight the economic and social benefits of supporting people with cancer to remain active in the society and has decided to start a collaboration with The Work Foundation to put together a proposal to conduct a project to quantify these benefits of social inclusion of cancer survivors and make the data accessible to policy-makers and other stakeholders.

The intervention will have the following objectives:

1. To produce a report highlighting the impact of improved cancer survival on the EU Economy and the wider society;
2. To produce an accessible, evidence-based and policy-relevant summary of the key data in relation to improved survival.

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## Implementation

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### ***Literature Review***

The Work Foundation will specify and conduct a review of the available literature on the social and economic impact of cancer in the EU. The review will include data on economic and social benefits to cancer survivors and their families, as well as the society. We will consider the different economic and policy contexts of the countries in the EU.

There are three main aims at the review: 1) To examine what the international literature tells us about the association between unemployment, disability and cancer and (lack of) access to appropriate services; 2) To identify the important factors that mediate and influence this relationship. This will include, for example, the role of labour market structures, healthcare policies and the current benefits system; 3) To set out the policy framework within which the EU operates. We could also consider a set of EU countries.

The Work Foundation will review the existing literature drawing on academic papers, grey literature, and reports and policy papers by organisations such as the European Union, national government, universities and think tanks.

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### ***International comparisons of effective interventions***

International perspectives are valuable in providing new ideas and insights, and so enrich the evidence base. While 'what works' in one country might not be directly replicable in another because of contextual differences. We propose two phases on the international comparisons:

#### **a) Analysis of costs and benefits of workplace interventions supporting cancer survivors**

Evidence will draw on examples from both the UK and internationally. We will utilise existing links with external organisations, for example, the Coronel Institute of Occupational Health in Amsterdam and the Centre for Work Health in Amersfoort, the School of Public Policy in the USA, and the Institute for Work & Health in Canada. Particular attention will also be given to Scandinavian countries, given the development in this region of several welfare policy initiatives to enhance work participation and social inclusion of people with long-term conditions.

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## **b) Programmes effectiveness assessment**

We will evaluate the cost-effectiveness of the international programmes reviewed here. We will take a research synthesis approach, utilising previous evaluation studies. This evaluation adopts a narrative, rather than meta-analytic approach, to summarize and synthesize the findings. This approach is appropriate due to the limited number of evaluation studies available assessing the same programme and employing similar evaluation methods.

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### ***Roundtable event***

We propose to host a half-day roundtable event at the European Parliament among key stakeholders (clinicians, economists, occupational health professionals, members of parliament and members of the European parliament, patient organisations, employers, European Organisation for Research and Treatment of Cancer, etc.) to share and debate our early findings and conclusions – and some of the issues being raised by the evidence - before finalising our report. This event will help us to refine the way we present our findings and to distil our recommendations.

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### Deliverables

- Literature Review
- Roundtable Event

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### Timeframe

- Month 0: Funding secured for project
- Month 1: launch of the initiative
- Months 2 – 8: Preliminary draft of the study to be discussed with main stakeholders
- Month 9: event at the European Parliament
- Months 10 – 11: revision of the study based on the discussion with relevant stakeholders
- Month 12: Public launch of the final report including recommendations

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## Capacity building activities

### **ECPC Annual Meeting 2017 (ongoing, confirmed)**

The ECPC Annual General Meeting is Europe's largest cancer patients gathering, hosting more than 120 cancer patients' organisations from over 20 European countries. Since 2013, the ECPC AGM has increased its capacity and scope, with over 140 participants in 2014 (Bucharest), 110 participants in 2015 (Brussels), and 150 participants in 2016 (Brussels).

Traditionally, the Assembly is divided into three 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 cancer patients;
- Sunday: General Assembly of the Association.

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 AGM.

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 2017 Action Plan will occur during the AGM, including:

3. Digital Photo Exhibition: Cancer Marks Us for Life
4. Working Group for Rare Cancers meeting
5. Working Group for Bladder Cancers meeting
6. Legal Network for Cancer Patients meeting
7. Session on multi-disciplinary care
8. Award ceremony of ECPC cancer survivor scholarships

The ECPC AGM will take place 16-18 June 2017, in Brussels, Belgium.

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## ECPC newsletter (ongoing, confirmed)

### Rationale and objectives

Information is cancer patients' first medicine.

In 2014 ECPC kicked off a newsletter service to inform ECPC Members 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 540 email addresses of high-level national and European cancer patients' organisations are included in the newsletter database. Thanks to Mailchimp, ECPC's newsletter system, we can monitor and analyse what our Members find more interesting, which consolidates our understanding of the ECPC Membership's needs. Therefore, we 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 for more than one year and a half.

In 2017 we would like to provide our Members with more information on policy and advocacy in cancer at the EU level. The objective is to continue to raise our Members' understanding of the complex EU public health policy panorama. This will serve the double purpose of making our work and achievements in policy better understood, and, most importantly, raise our Members' awareness on the impact of EU health policies on their life and how they can proactively contribute to our policy work.

### Implementation

The ECPC Newsletter will cover news and information regarding ECPC's activities and projects. The ECPC Newsletter will be produced by the Community Manager, in collaboration with the Public Affairs Coordinator and the Project Office, and under the final supervision of the Director. The Community 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.

### Deliverables

- 13 ECPC Newsletters in 2017.

#### 5.2.4. Timeframe

- January – December 2017: production of 12 ECPC Newsletters (once a month) + 1 special issue.

## Training the survivors of tomorrow (ongoing, confirmed)

A life saved from cancer is invaluable. The life of a child saved from cancer is possibly even more precious. For this reason, ECPC intends to grant 5 scholarships to further enrich the life of 5 teenage and young adult's cancer survivors needing help to continue their education, for personal growth and a better, brighter future. The scholarships, of 1500 euro each, will be handled during the ECPC AGM.

All ECPC Members (Full and Associate) can present one candidature. The candidates need to send an organisation, will need to send a motivation letter, explaining:

- Their cancer journey;
- What did she or he learn from their cancer experience;
- What are the thoughts and intentions about the future: studies, profession, etc.?

The motivation letter will be assessed by the ECPC Board.

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## Rare cancers working group (new, confirmed)

### Rationale and objectives

The Joint Action on Rare Cancers (JARC) and the European Reference Networks (ERN) are crucial game changers for rare cancer patients in Europe. The European Cancer Patient Coalition (ECPC) is honoured to contribute and represent the needs, rights and hopes of rare cancer patients in the Joint Action on Rare Cancers since rare cancers have been a priority for ECPC since its creation.

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 AGM 2016, ECPC has established a Working Group on Rare Cancers (WGRC), working in parallel with the JOINT ACTION ON RARE CANCERS (JARC), 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.

### Implementation

The key objective of the WGRC 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 WGRC members will also have the opportunity to use the platform to decide on further topics for discussion, of interest to rare cancer patients, e.g. the ERN implementation, the Orphan Drugs Regulation and the Paediatric Regulation. The aim of the WGRC 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 twice a year: once in a dedicated session during the AGM, and once during a dedicated meeting, to be organised by ECPC. The WGRC will also meet at least 4 times a year via teleconference.

ECPC will ensure the dissemination of the activities of the WGRC, including all the documents approved by the WGRC. ECPC will offer administrative and policy formulation support to the WGRC.

### Timeframe

- September 2016: closing of applications and announcement of members
- October 2016: First meeting of the WGRC to match the launch of the JARC
- June 2017: Meeting of the WGRC during the ECPC AGM 2017

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### **Building a sustainable internship programme (new, confirmed)**

Thanks to the ECPC Office, we managed to increase the number of quality of our initiatives greatly since 2013. However, the increasing budget and responsibilities need to be supported with appropriate staffing. For this reason, in 2017 ECPC will put together a solid internship programme to support the policy and communication work.

ECPC will facilitate and prioritise the application from young cancer survivors.

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## Collaborations

### OECI (ongoing, confirmed)

The signature of a Memorandum of Understanding in September 2015 between ECPC and [Organisation of European Cancer Institute \(OECI\)](#) marked a milestone for cancer advocacy: Europe's largest cancer patients' association 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 our disposal.

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

#### The Joint Declaration

The Joint Declaration will outline the vision that ECPC and OECI 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 OECI 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;
  - Etc.

The preparation of the Joint Declaration will be underpinned by a scientific paper in the field of ethics and organisation management, which will describe the methodology used to write the Declaration.

Following this structure, the Joint Declaration will be 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 will make the Joint Declaration time-proof and also easily adaptable to the new needs and new rights of cancer patients.

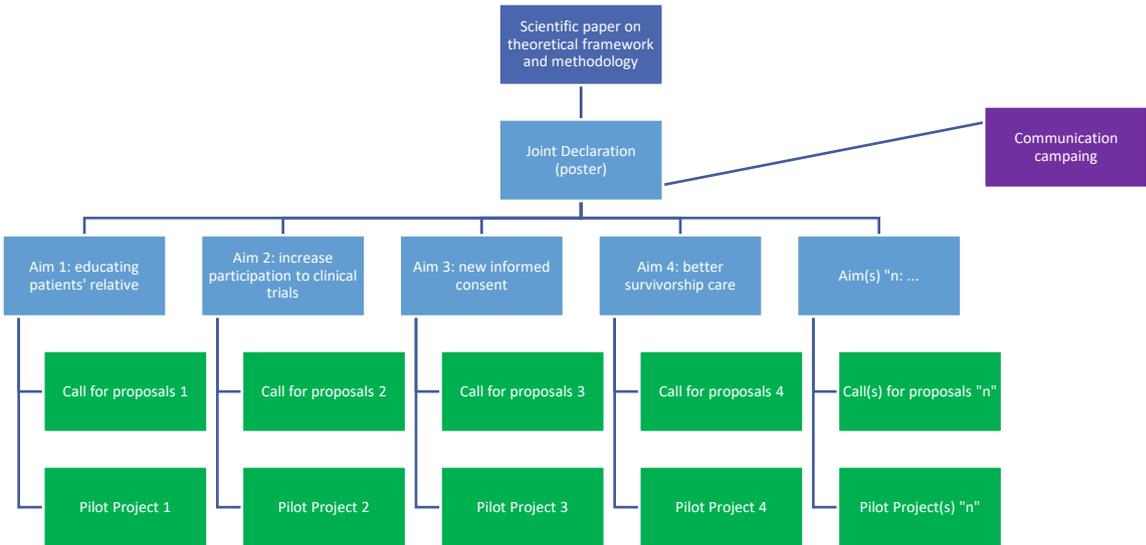
**Pilot projects**

Based on the principles of the Joint Declaration, ECPC and OEI Members will work together to establish pilot project on the specific aims identified by the Joint Declaration. Each pilot project will develop in real life one of the AIMS of the Joint Declaration.

From March 2017, ECPC and OEI will launch calls for expression of interest to both association’s Memberships, with the details concerning the aim and some hint on what kind of projects can be implements. ECPC and OEI Members will be asked to respond to the call, stating their interest and suggesting possible pilot project concepts. ECPC and OEI will shortlist the most interesting and feasible ideas, in line with the principles of the Joint Declaration, and will organise scoping projects meeting with ECPC-OEI Members, in order to finalise the pilot projects’ timeframe, budget and deliverables.

The pilots will be organised in those cancer centres where we can identify one ECPC and one OEI Members ready to collaborate. Each pilot project partners will autonomously decide how to implement the project, respecting the spirit and aims of the Joint Declaration. The pilot project’s partners will have to nominate a project coordinator each, who will serve as the contact person and main responsible for the project. The two projects coordinator will work in close collaboration with ECPC and OEI staff involved in the drafting of the Joint Declaration, who will provide support to the pilot project’s partners in developing the initiatives.

The implementation of each pilot projects will be managed by the local ECPC and OEI Members, under the supervision of ECPC and OEI staff, who will serve as counsellors. To facilitate the implementation, ECPC and OEI will provide the selected pilot projects’ idea with a core funding of 10.000 per project, which will be manged in partnership by the ECPC and OEI Members selected for the pilot project.



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## Deliverables

- The Joint Declaration, composed of
  - The poster presenting the three principles of the Joint Declaration and the main aims
  - Four developed aims, providing practical guidance of 4 achievable objectives of the Joint Declaration
  - The scientific paper explaining the methodology behind the creation of the Joint Declaration
- 4 pilot projects
  - Coordinated by a pair of ECPC-OECI Members in loco
  - Under the supervision of ECPC and OECI staff
- Dissemination campaign to raise awareness on the Joint Declaration, including:
  - A dedicated website
  - Communication kit composed of
    - A poster summing up the Joint Declaration;
    - A booklet including the four aims and the scientific paper;
    - Tips to promote the uptake of the Joint Declaration at local level.

## Timeframe

- January 2017: presentation of the Joint Declaration at the European Cancer Congress 2017 in Amsterdam (dedicated session);
- January 2017: launch of the Joint Declaration dedicated website;
- January – March 2017: finalisation of the dissemination campaign's material
- March – July 2017: launch of the 4 pilot projects' calls for expression of interest
- July – September 2017: identification of the pilot projects' participants and definition of each pilot project specific objectives, deliverables, budget and timeframe (project negotiation);
- September 2017: kick off of the first pilot project;
- October – December 2017: kick offs of the other three pilot projects.

## ECPC – OECI Charter of Cancer Patients' Rights in Cancer Institutes

Patients and healthcare professionals live the fight against cancer from two different perspectives. Yet, they tend against the common enemy, such as that the long voyage of cancer patients is often best seen and shared by the physicians and nurses supporting the patients.

Born from an initial idea of Dr Dominique de Valeriola, the proposal will be based on the overarching values enshrined by the European Cancer Patient Bill of Rights, detailing the specific rights of cancer patients in the cancer institutes' setting, providing a model for collaboration between patients and physician.

The Charter will be produced by a panel of expert ECPC Members and OECI institutes and translated in several languages. Each ECPC Member and OECI institute will then be asked to promote the Charter at the national level.

ECPC and OECI will, in the meantime, promote the Charter as a model for collaboration at the European level, disseminating it within the relevant EU initiatives existing (CanCon, EU projects etc.) and through a launch event at the European Parliament.

## Timeframe

1. January 2017 (ECCO2017): presentation of the initiative;
2. January - April 2017: production of the Charter;
3. March - July 2017: finalisation of the Charter and presentation of the draft to ECPC and OECI Members;
4. November 2017: finalisation of the Charter and launch event at the European Parliament.

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## ESMO (ongoing, confirmed)

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 cancer patients 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 2017, ECPC and ESMO will work to implement the agreement and commitments taken in 2016.

### ESMO Guidelines

ECPC will be 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.

### handbook on survivorship

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 cancer patients 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 cancer patients 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 cancer patients and allowing them to return to a normal life.

ECPC and ESMO will therefore work 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.

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## **UICC (ongoing, confirmed)**

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.

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## EORTC (new, pending)

clinicaltrials.ecpc.org

### ***Rationale and objectives***

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?

These are few of the questions that European cancer patients have about clinical trials. During the ECPC-EORTC Clinical Trials Seminar 2016, a very interactive session on this topic animated a debate on the above-mentioned questions. The outcome was clear: patients want to know more on clinical trials, and researchers need more patients to undergo crucial clinical research and deliver significant results.

ECPC strongly believes that clinical trials are beneficial for the patients because of the high standards of European clinical research. CTs in cancer are very different from trials in other disease areas: given the potency and side effects of cancer treatments, cancer CTs cannot be ethically performed on healthy subjects. Yet, cancer is the first killer in 17 out of 28 EU Member States, therefore obliging our societies to invest more and more in clinical research. It is not all about the development of new treatments: in many cases in fact, like for paediatric cancer patients, clinical trials represent the only way to access possibly life-saving treatment and/or the best cure available. Academic clinical trials are crucial to understand how we can use the resources we currently have in a better way, yet providing patients with better services. The high standards of safety and control of clinical trials in Europe, furthermore, ensure cancer patients with possibly the best follow up from medical professionals. Clinical trials are therefore a crucial resource for cancer patients. For all these reasons, ECPC believes that more patients should have the chance to access the right trials for them.

Yet, only 5% of all the eligible patients take part into a clinical trial, therefore profiting of their added value. 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 are 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 2 initiatives to solve these issues:

- a web-portal dedicated to explain to cancer patients what clinical trials are, inspired and guided by the comments and feedback received during the ECPC-EORTC Clinical Trials Seminar;
- 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.

### ***Implementation***

The Portal

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

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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 CTs 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 we 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 has to do with 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, we need also to ensure that such patient-centric content is translated in as many languages as possible. The language barrier has been consistently mentioned by our members as their principal problem in sharing ECPC work at the national level, sensibly dwarfing our impact at the grassroots level, where help is more 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.

The clinical trials database

ECPC has published, first 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 organisations, shares our same concerns: patients are just not made aware of all the possible trials they can participate to. The first problem to solve would be to create a tool to provide the informed patients with a complete overview of the opportunities existing.

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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 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 our Members willing to provide it to their members.

### ***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.

### ***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.

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## Research projects

### **Innovative Medicines Initiative (new, confirmed)**

DO-IT (new, confirmed)

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.

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.

This project will run from 2017-2019.

ECPC will be involved in dissemination and communication (WP3) and in the development of the Informed Consent Forms as well as the training materials (WP4).

Prefer (ongoing, confirmed)

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 2016-2020.

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.

### **Horizon2020 (ongoing, confirmed)**

H2020mm04 (Mesothelioma) (ongoing, confirmed)

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.

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The main objective of the project is to demonstrate the efficacy of DC-based immunotherapy in a randomised phase II/III clinical trial in order to address this urgent need. This could potentially lead to a cure of asbestos-exposed workers, consumers and patients. The project will run from 2016-2019.

ECPC will be involved in WP6, the WP responsible for the effective dissemination and exploitation of the results to external stakeholders. ECPC will disseminate the project news and results to all its member patient organisations via the monthly 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.

#### IMMUNOSABR (ongoing, confirmed)

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 is a 6-year project and will run from 2016-2022.

Palliative treatment is the current standard of care for patients with metastatic non-small cell lung cancer (NSCLC), unless there is an actionable mutation. By using the concept of limited metastatic disease, the project aims to develop a therapy with curative intent. IMMUNOSABR will gather evidence for the clinical efficacy of the bi-modal treatment strategy mentioned above in a multicentre randomised phase II study in patients with limited metastatic NSCLC. IMMUNOSABR is complemented by two strong biomarker work packages which focus on developing an ambitious personalised biomarker strategy, to identify patients who can benefit from the novel treatment strategy. This includes promising non-invasive imaging techniques and state-of-the-art immunological monitoring approaches on tumour tissue and blood.

Through ECPC, the consortium will receive input regarding the development of the informed consent and the brochure that will be used to inform patients. The ECPC will provide a platform for panel discussions with patients regarding the clinical trial design (organization of consultation). In addition, ECPC will promote the communications of the IMMUNOSABR trials through its own network and supports with the communication towards

#### Transcan-2 (ongoing, confirmed)

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

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.

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The Italian Ministry of Health and the National Institute of Health act as Joint Call Secretariat (JCS). ECPC is represented in the Scientific Advisory Board (SAB), one of the three main governing bodies of the network. The SAB 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 (NSC), as the strategic decision-making body and the Network Coordination Unit (NCU), as the body responsible for the day-to-day management and the external TRANSCAN consortium representation.

## **7th Framework Programme (ongoing, confirmed)**

eSMART (ongoing, confirmed)

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 (NHL, HL) 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.

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 cancer patients. 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 cancer patients reduce the symptom burden experienced during chemotherapy and improve their quality of life (QoL) during acute treatment and survivorship. Most important, the project results will facilitate changes in clinical practice thus, leading to improved delivery of cancer care. The project will run from 2014-2019.

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, in the Exploitation Committee, offering advice and feedback to ensure that the trial is designed and conducted in line with patients' needs and preferences.



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**NOTHING ABOUT US, WITHOUT US!**

European Cancer Patient Coalition – ECPC, January 2017  
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