



EUROPEAN CANCER PATIENT COALITION

“Nothing about us without us!” ECPC

ECPC is the unified voice of cancer patients across Europe

The European Cancer Patient Coalition (ECPC) works for a Europe of equality, where all European cancer patients have timely and affordable access to the best treatment and care available, throughout their life. ECPC believes that cancer patients are the most important partners in the fight against cancer and against all the cancer-related issues affecting our society. Policy makers, researchers, doctors and industry should recognise cancer patients as co-creators of their own health.

The European cancer patient Coalition participates in several European Union's Research and Innovation framework programmes, among others: this includes [IMI 1](#) projects, the [Seventh Framework Programme \(FP7\)](#) and [IMI 2](#) projects under the current [Horizon 2020 \(H2020\)](#).

Nutrition in cancer care – more important than you think!

On 9 November 2017, European Cancer Patient Coalition (ECPC), Sapienza University of Rome, and Healthcare International analysed the importance of nutrition for people with cancer during a meeting at the European Parliament with the participation of MEP Daciana Sarbu.



THE ROLE OF NUTRITION IN CANCER CARE

Thursday, 9 November 2017, 12:30 - 13:30
European Parliament, room A3H-1

Hosted by MEP Daciana Octavia Sârbu (S&D, Romania)



Nutrition is a crucial component of cancer treatment and rehabilitation as it helps patients to better cope with illness. Giving assistance and practical guidance to the patients on how to eat better daily, is a priority especially during therapy.

ECPC sent out extensive surveys on nutrition to directly address individual cancer patients and cancer survivors. This event gave the opportunity to hear about the surveys' results, to launch the consultation for ECPC's nutrition booklet and a proposal for a Patients' Charter of Rights to be adapted at EU level.

We brought together stakeholders, expert audience from the Commission, Member States representatives, patient advocacy groups, health economists, academia, other MEPs and key players.

For more info read [here](#).



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CHORDOMA days: advancing a very rare cancer

European Cancer Patient Coalition (ECPC) Projects Coordinator, Isabelle Manneh-Vangramberen, attended the 2-days meeting (27-28 September 2017) on Chordoma in Milan, presenting the “EU Patient Preservative: Chordoma as a model”.



ECPC Projects Coordinator, Isabelle Manneh-Vangramberen, shared the patient perspective and highlighted patient organisation' role in shaping the EU health policy agenda. She emphasized the need to bring together academia, regulators and patients in healthcare policy development and recognise patients as co-creators of their own health.

The meeting was the opportunity to discuss about patient empowerment in rare cancers and Chordoma in the EU regulatory environment. Other topical themes were under debate: rethinking pharmaceutical productivity, the evolving role of CDMOs, the changing demographic of drugs, patient centricity.

Agenda available [here](#).

Joint Action on Rare Cancers (JARC) WP10 Kick Off Meeting



ECPC is one of the patient organisations representing the needs, rights and hopes of rare cancer patients in the Joint Action on Rare Cancers (JARC) which aims to integrate and maximize efforts of the European Commission and EU Member States to advance quality of care and research on rare cancers. Accordingly, ECPC has established a **Working Group on Rare Cancers (WGRC) working in parallel with the JARC**, to guarantee that many rare cancer patient organisations, representing different European countries and rare cancer types, will be able to contribute to its activities.

On the 20 February 2017 JARC partners met in Barcelona, Spain to discuss **WP10 Rare Cancer Policy** which built on and integrated the outcomes from all WPs related to policy recommendations to compile them through a common framework. This Work Package is coordinated by the **Catalonian Institute of Oncology**.

More info [here](#).



PREFER Annual Meeting



Patient Preferences in Benefit-Risk Assessments during the Drug Life Cycle (PREFER) is a five-year project funded by the European Commission's Innovative Medicines Initiative (IMI) 2 programme to evaluate different ways of assessing clinical patient preferences.

The project aims at strengthening patient-centric decision making throughout the life cycle of medical products by developing expert and evidence-based recommendations to guide the different stakeholders (industry, regulatory authorities, HTA bodies, reimbursement agencies, academia, health care professionals and patient organizations) on how and when patient preference studies should be performed, as well as how the results can be used to inform decision-making.

Patient organisations provide a strong and united patients' voice, placing patients at the centre of EU Health policy and the forefront of research programmes. Through various Innovative Medicines Initiative (IMI) projects, including PREFER, patient advocates voices are becoming increasingly present in all aspects of drug development: from fundamental research to regulatory aspects, pricing and reimbursement decisions at the EU-level.

The annual meeting of the PREFER project was convened on **October 26-27th 2017**. We presented and discussed the Project's progress with members of the consortium and invited stakeholders.

Francesco De Lorenzo, President of ECPC, participated in a roundtable for the patients' session, while **Isabelle Manneh-Vangramberen** will moderate the session as the Patient Advisory Group (PAG) Lead.

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More info [here](#).



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Big Data for Better Outcomes Annual Meeting



The Big Data for Better Outcomes, Policy Innovation, and Healthcare Systems Transformation (BD4BO-DO>IT) is a two-year project funded by the European Commission's Innovative Medicines Initiative (IMI) 2 programme. The consortium coordinates the IMI 2 Big Data for Better Outcomes (BD4BO) programme, identifying and addressing opportunities for data-driven healthcare system transformation.

Over the next two years, the Big Data for Better Outcomes, Policy Innovation, and Healthcare Systems Transformation (**BD4BO-DO>IT**) consortium will coordinate the IMI 2 Big Data for Better Outcomes (BD4BO) programme, identifying and addressing opportunities for data-driven healthcare system transformation based on input from healthcare systems stakeholders and on knowledge, data and tools developed in the BD4BO disease specific projects: **Alzheimer's Disease, hematologic malignancies, cardiovascular diseases and prostate cancer.**

More info [here](#).



Big Data for Better Outcomes in Healthcare

BIG DATA FOR BETTER OUTCOMES IN HEALTHCARE

public lecture and panel discussion

Dr Jem Rashbass Keynote lecture
Public Health England

Technische Universität Berlin
9th October 2017 17:30 – 19:00



The big data revolution promises transformational potential for healthcare through data-driven improvements in research & development, care delivery, and policy-making. As health systems around the world routinely collect a wealth of data every, we are facing the question: how can we use big data to improve patients' lives?

On 9 October 2017, in a public lecture at the Technische Universität of Berlin, Dr Jem Rashbass (National Director Disease Registration and Cancer Analysis at Public Health England) outlined how health systems can turn big data into information. A high-profile panel commented how this information can be use, implications of big data for healthcare system transformation, and patients' perspectives on the collection and use of highly personal data.



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ESO-ESMO-RCE Clinical Update on Rare Adult Solid Cancers



On **2-4 December** in Milan there was a **ESO-ESMO-RCE Clinical Update on Rare Adult Solid Cancers**. The course was organised by [Rare Cancers Europe \(RCE\)](#) in collaboration with the [European School of Oncology \(ESO\)](#) and [European Society for Medical Oncology \(ESMO\)](#).

This [ESO-ESMO-RCE](#) joint event was aimed at dealing with them on an annual basis, to provide the community of clinical oncologists specialising in these tumours with a regular update of recent advances in this specific area. The goal is to strengthen the educational coverage of a group of cancers which may be neglected despite their collective incidence.

ECPC President, Francesco De Lorenzo, moderated the *Patient Empowerment in Rare Cancers* session and presented the European Union scenario on Saturday 2 December from 11:30 to 13:00.



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