



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 \(H2020\)](#).

JOIN NOW



INVITATION

ROLE OF NUTRITION IN CANCER CARE

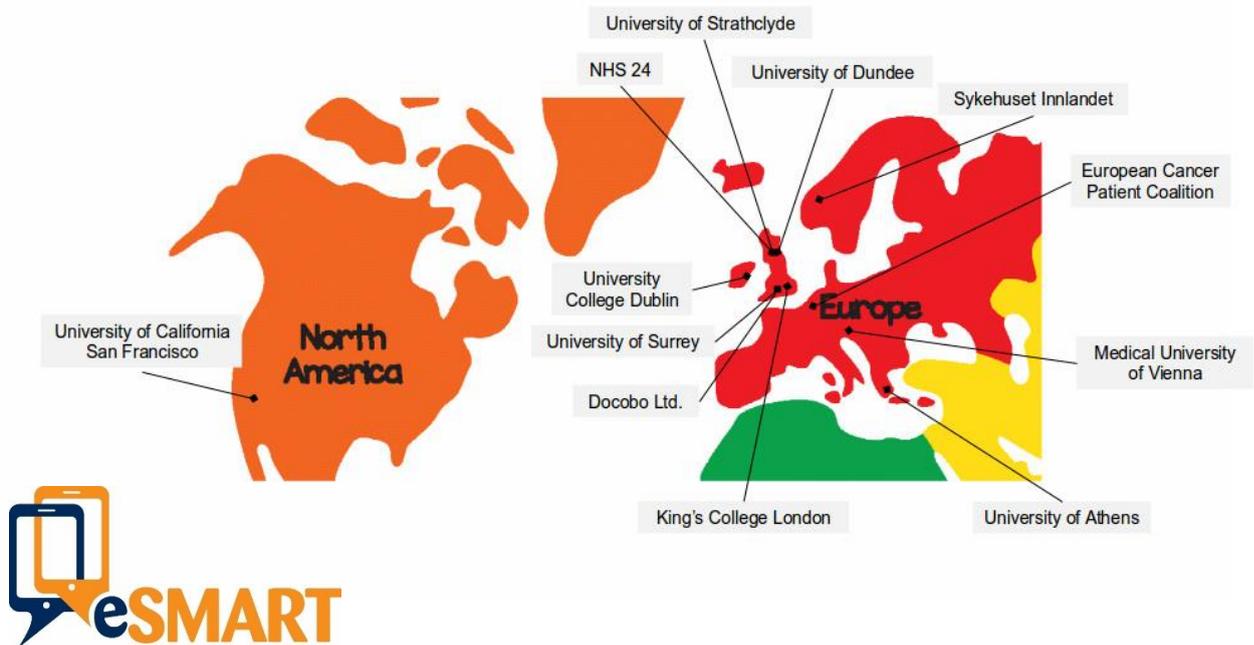
Thursday, 9 November 2017, 12:30 - 13:30
European Parliament, room A3H-1

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



eSMART Consortium Meeting

The **e-Symptom Management** using advanced symptom **Management System Remote Technology (eSMART)** is funded by the European Commission's **Seventh Framework Programme**. The clinical trials aim to evaluate the impact of a mobile phone-based, remote monitoring, symptom management intervention (Advanced Symptom Management System, ASyMS) on the delivery of care to people diagnosed with non-metastatic breast, colorectal or hematological cancer during chemotherapy and for one year after treatment.



Benefits to cancer patients undergoing chemotherapy include:

- Reduced symptom burden
- Improved quality of life
- Informed changes in clinical practice and delivery of care

After six months of prearrangements, this year's eSMART Annual Consortium Meeting was held in at the **Campus of the Medical University of Vienna** from **March 28th till 30th 2017**. The meeting welcomed an overall of 23 attendees and members of the consortium who discussed latest updates within the various work packages overall and implementation challenges faced. ECPC was represented at the meeting by Vice President Kathi Apostolidis and Projects Coordinator Isabelle Manneh-Vangramberen.

For more information read [here](#).



Contact us [here!](#)



Working Group on Rare Cancers (WGRC) 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**, in order 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 its activities.

On the **16 June 2017**, ECPC held the second Working Group face-to-face meeting at the Renaissance Hotel in **Brussels, Belgium**. The meeting was chaired by Yana Pelouchova, ECPC General Secretariat and CML patient, by the two vice chairs: Laura D'Avanzo from Glioblastoma Multiforme - Cancro al Cervello, Italy and Mary Skehan from Slainte an Chlair, Ireland, and facilitated by Projects Coordinator Isabelle Manneh-Vangramberen. The meeting was also attended by ECPC President Professor Francesco De Lorenzo and Director Dr. Lydia Makaroff.

During the meeting, members of the WGRC introduced themselves and their organisations and shared with ECPC their priorities and challenges they face in their respective countries with regards rare cancers. WGRC Chair Yana **Pelouchova** introduced ECPC Activities within the JARC, while Dr. Annalisa Trama presented an overview of the **Joint Action on Rare Cancers** from the definition of a Joint Action to the overall objectives of the **JARC**. Dr. Trama's presentation was followed by the presentation of Isabelle Manneh-Vangramberen who shared an overview of the activities going on in rare cancers in Europe namely on the **European Reference Networks (ERNs) and the ERN on Rare Adult Solid Cancers (EURACAN)**.

Latest Project Deliverables: 65-member organisations recruited within the WGRC, online platform kick-off, vice chairs elected, web conference meeting, JARC Poster, JARC brochure, dissemination of JARC tools, mapping of RC news and events, mapping of RC patient educational material, dissemination of RC tools, ECPC AGM 2017-WGRC meeting, and ECPC AGM 2017- presentation.

For more information read [here](#).



Contact us [here](#)!



PREFER Steering Committee 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 is to strengthen 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.

On **31 May** and **1 June 2017** at **Merck Offices in Darmstadt, Germany** members of the consortium and invited stakeholders discussed project's progress where ECPC Projects Coordinator, Isabelle Manneh-Vangramberen, moderated the session as the Patient Advisory Group (PAG) Lead and, later, interviewed for a PREFER article on the '[Patient Voice in Preference Studies](#)'.

Latest Project Deliverables: website launch, defining key Performance indicators, data management plan, dissemination and communication Plan, and WP2 reports on patient preference elicitation issues and approaches, and ECPC AGM 2017-PREFER presentation.

For more information read [here](#).



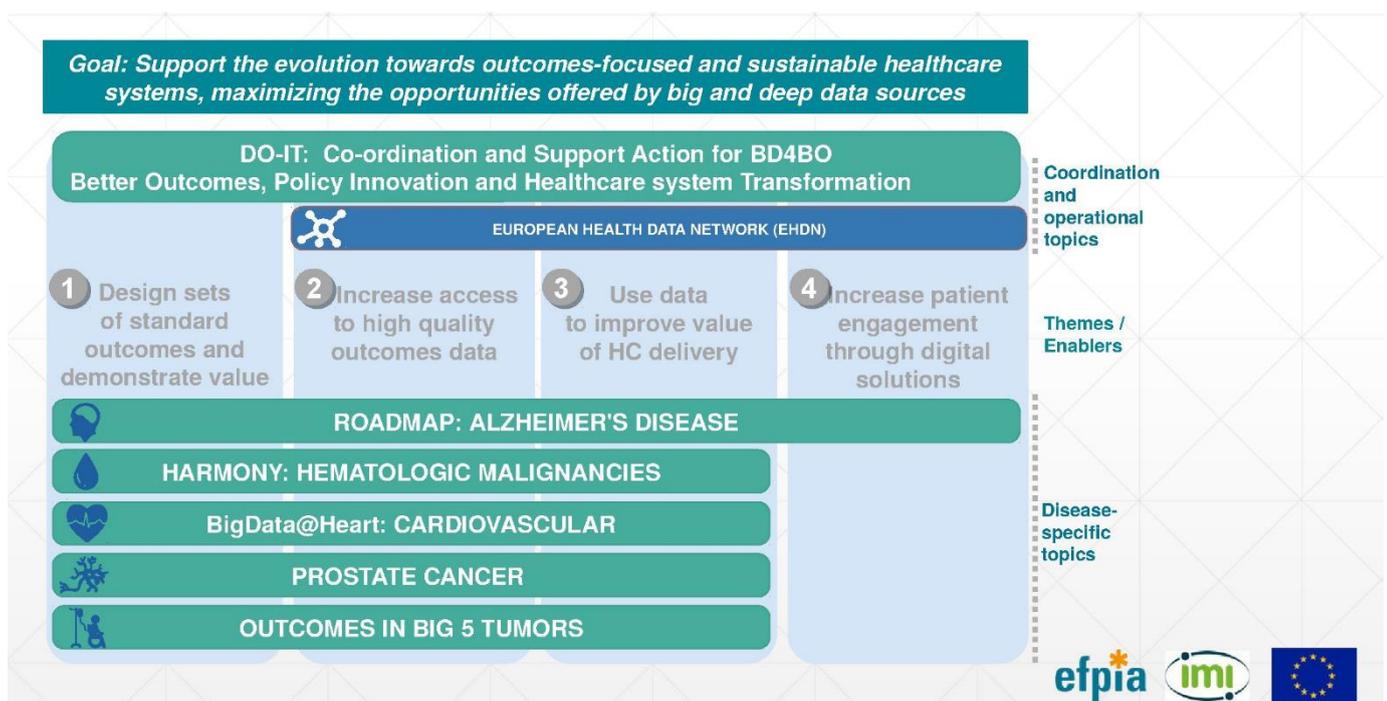
Contact us [here!](#)



Big Data for Better Outcomes WP3 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.



On the **19-20 June 2017** at the **London School of Economics, UK** ECPC participated along with Work Package 3 partners to discuss communication strategies and collaborations as part of the **BD4BO-DO>IT** project meetings.

Latest Project Deliverables: website launch, Connecting the dots: Putting Big Data to work for Health Systems in Eurohealth Observer.

For more information read [here](#).



Contact us [here](#)!

