



## Lessons to address the poor state of COPD care in Europe and research in Horizon 2020



To mark **World Chronic Obstructive Pulmonary Disease (COPD) Day 2013**, the European COPD Coalition (ECC) (1), and the European Federation of Allergy and Airways Diseases Patients' Associations (EFA) (2) organised an event (3) under the auspices of the Lithuanian Presidency of the Council of the European Union (EU). The conference entitled "[What role for diseases and patients in shaping Horizon 2020? A COPD case study of patient involvement](#)" discussed the EU Framework Programme for Research and Innovation – Horizon 2020, and standards of care for COPD, with a patient's perspective.

**COPD (4) was taken as a case study**, since this chronic lung disease is marked by increasing prevalence among the European population and is **one of the leading causes of premature deaths worldwide and yet**, awareness of the COPD is largely insufficient.

**The degree in which Horizon 2020** – the financial instrument implementing the Innovation Union: an EU initiative aimed at securing Europe's global competitiveness- **is fit to accommodate disease specific research featured high during the debate.** "*Given the prevalence and societal and economic burden of COPD, there should absolutely be some kind of ring-fencing of funds for specific diseases such as this that has been underfunded to date. In such areas, researches would otherwise find it hard to compete with larger, more established research fields. Additionally, prevention and patient priorities have been neglected for far too long and should be moved up dramatically in the agenda,*" said Mike Galsworthy, from the University College London's Department of Applied Health Research.

*"The clock is ticking when it comes to tackle the acute deficiencies in the way that COPD is treated across Europe. **Patients themselves should be given a larger role in shaping research**, for instance, in prompting actions – i.e. to be better integrated in EU projects – **so that policy-makers and healthcare professionals do not trip over the same stone again when delivering care to patients,**"* pointed out Isabel Saraiva, COPD patient from the Portuguese Association of people with COPD and other Chronic Respiratory Diseases (RESPIRA).

**EFA's report 'Minimum Standards of Care for COPD Patients in Europe' (5) was launched during the conference.** "*As the EFA's paper highlights, people suffering of COPD and patients of respiratory diseases in Europe have been enduring for decades large disparities in the standards of care received. To overcome these inequalities, **patient-driven standards on prevention, diagnosis, care and rehabilitation have to be better measured. There is an urgent need to use this data to drive and improve patients outcomes,***" stated Rupert Jones, General Practitioner for the International Primary Care Respiratory Group.

Over the course of the event, **EFA's booklet 'Enabling Air Travel with Oxygen in Europe' (6) was presented** as a case study for ongoing discrimination against patients with chronic respiratory diseases.

— end—

### Notes to editors

(1) [The European COPD Coalition \(ECC\)](#) is a not-for-profit association under Belgian law, based in Brussels, whose role is to advocate for political action to be taken at the European level to reduce the burden of the disease

through collective action and campaigns, seeking the development and implementation of a comprehensive EU public health policy on COPD. ECC aims to be a key facilitator of COPD health policy initiatives at European level. The ECC works with all parties interested in fighting COPD and public health officials to boost awareness of chronic obstructive pulmonary disease (COPD) and decrease the morbidity and mortality caused by this respiratory illness, through advocacy and policy development.

(2) [The European Federation of Allergy and Airways Diseases Patients' Associations \(EFA\)](#) is a non-profit network of allergy, asthma and COPD patients organisations, representing 35 national associations in 22 countries and over 400,000 patients. EFA is dedicated to making Europe a place where people with allergies, asthma and COPD have the right to best quality of care and safe environment, live uncompromised lives and are actively involved in all decisions influencing their health.

(3) This event displayed a wide range of speakers, like Members of European Parliament, researchers, health care specialists, COPD patients. It also included a lung testing (spirometry) for free at the venue.

(4) Chronic Obstructive Pulmonary Disease (COPD) is the only major chronic disease whose incidence is on the increase and is expected to be the third leading cause of death worldwide by 2030 (exceeded only by heart diseases and stroke). [You can learn more about the incidence of COPD here.](#)

(5) [Minimum Standards of Care for COPD Patients in Europe](#)

(6) [Enabling Air Travel with Oxygen in Europe](#)

#### **Contact information**

Catherine Hartmann, the European COPD Coalition (ECC) Secretary General at [info@copdcoalition.eu](mailto:info@copdcoalition.eu) or Tel. [+32 \(0\) 2 230 59 33](tel:+3222305933)

Susanna Palkonen, the European Federation of Allergy and Airways Diseases Patients' Associations (EFA), Executive Officer at [info@efanet.org](mailto:info@efanet.org) or Tel. [+32 \(0\) 2 227 27 12](tel:+3222272712)