A Report on the "What role for diseases and patients in shaping Horizon 2020? A COPD case study of patient involvement" Event

Hosted by:

The Lithuanian EU Presidency

Organised in collaboration by:

The European COPD Coalition (ECC)

The European Allergy and Airways Diseases Patients' Associations (EFA)

On the 28th of November 2013, the **European COPD Coalition (ECC)** and the **European Federation of Allergy and Airways Diseases Patients' Associations (EFA)** celebrated **World Chronic Obstructive Pulmonary Disease (COPD) Day 2013** together at a public event offering a diverse range of discussions focusing on the implications of "Horizon 2020" on patients, healthcare professionals, academia and European citizens. The case of COPD was used to contextualise important questions concerning health research for single disease areas, the assurance of adequate standards of care through research and patient involvement. The event was structured into three different sessions and offered spirometry testing for participants throughout the day to raise awareness of COPD and the need to increase its use as a tool for early diagnosis.

Deputy Health Attachée from the Lithuanian Presidency of the Council of the European Union, **Giedrė Medžiaušaitė**, welcomed guests to the event and she opened the discussion in expressing alarm at the rising COPD prevalence in Europe, which the WHO predicts to become the third leading cause of death among chronic diseases in the world. She explained measures the Lithuanian Presidency have supported in healthcare and confirmed Council Conclusions on the "Reflection process on modern, responsive and sustainable health systems," which were adopted on December 10th, would include the necessity to strengthen health in all policies and principles, while ensuring patient empowerment and the use of best practices.

EFA President, **Breda Flood**, followed up with remarks concerning the importance of commemorating World COPD Day as a means to improve awareness and care for COPD patients around the world. In addressing both COPD as a disease affecting many people, while remaining underreported by the media, Horizon 2020 was acknowledged as a major driving force which can help pushing COPD onto research and political agendas. She emphasised the need for patient-centred and driven research projects, pointing to EFA's recent work as examples of publications responding to this need, in particular the launch that day of *EFA Book on Minimum Standards of Care for COPD Patients in Europe*. **Dr. Sylvia Hartl**, from the European Respiratory Society, member of[1] and representing the ECC, stated that the importance of addressing COPD cannot be understated. She alerted the audience that European costs from COPD, €141 billion, presently exceed the investment in Horizon 2020, which is the highest funded research programme in Europe.

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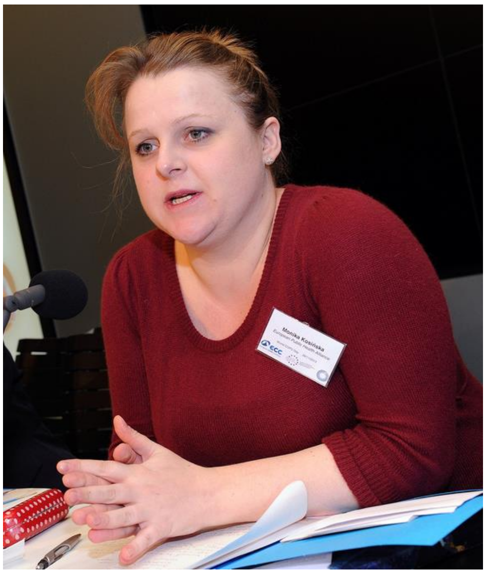
[1] **Note:** ERS is a member of the ECC until the end of 2013

Is Horizon 2020 fit to accommodate for disease specific research?

Implications of Horizon 2020 for public health and quality care

The first session began with Research Programme Officer, **Dr. Grigorij Kogan**, from DG Research and Innovation of the European Commission (EC) presenting the implications of Horizon 2020 (H2020) on public health and quality of care. With health research included in the "Cooperation Programme," there have been 29 collaborative projects supported in this area to date with a total funding for projects related to COPD totalling € 30 million by FP7, the previous European Commission funding programme for research and innovation. He confirmed an increase in funding for H2020 in comparison to FP7 was justified by a strong focus on the part of the European Commission on healthcare. He added that H2020 brings an opportunity to propel Europe forwards as global research leaders while health is categorised under 'societal challenges.' So while specific diseases are not mentioned in H2020, COPD can be considered a societal challenge. In his opinion, research aims should include and value industrial or economic returns. Answering questions on the importance of research on preventing diseases, he mentioned that the draft work programmes include projects on the matter, acknowledging that only 3% of funding goes towards this area. He noted the difference between research of prevention and prevention itself, stating the latter usually falls into being a national competency of health programmes.

The role of the European Parliament and Member States and their influence



"The biggest political challenge will be to couple industrial objectives with beneficial outcomes for society."

-Monika Kosińska, Secretary General of the European Public Health Alliance

Monika Kosińska, Secretary General of the European Public Health Alliance (EPHA) then addressed the role of the European Parliament and Member States in shaping the content of H2020. She warned of potential competition between specific disease areas for research funding and critiqued the difference between industrial and social objectives in health research. She further highlighted the growing tension between growth and health as needing to be acknowledged publically and more frequently. She pointed to COPD as a classic case of how a 'needs-based' societal approach is extremely important as healthcare access, methods and systems are all determinant of quality in care. New developments do not always translate to high returns financially or in day-to-day healthcare and new research investments must be conscious of this reality. She advised caution in pushing investment to the wrong projects and concluded by acknowledging H2020 as a phenomenal policy driver which will shape the research and political landscape, but it should not subsidise the growth of healthcare inequality.

How will Horizon 2020 work for health research?

Mike Galsworty, a Senior Research Associate from the Department of Applied Health Research at the University College London, presented an academic perspective on ways Horizon 2020 could work for health research. He shared results from a study on health research funding in the EU evaluating how it has changed and where it is going. He highlighted the fact that 80-90% of "mega" health projects with global collaboration and huge funding have more publications in peer reviewed journals, more references and citations than smaller counterparts. A major improvement was identified as necessary with regards to the national Ministries of Health, which were referred to as "broken conduits" between the European Commission and researchers. There was also concern expressed for the potential distortions regarding topics selected for research because of how PhD students decide upon their areas of study and encouraged structuring of subject selection based upon societal needs. He presented the audience with four specific recommendations, which included:

1. *Cut out destructive bureaucracy*
2. *Research mapping inputs: make identification of what was funded easy*
3. *Research mapping outputs: improve dissemination of project results and systems to making them accessible*
4. *Eastern European problems of lower participation and underfunding, including local salary issues*

To conclude, he identified missing elements to H2020 including help for interactions between small-medium enterprises and academia because it is a more recent development.

World COPD Day 2013

November 20, 2013

The event is to mark World COPD Day, which is an annual awareness-raising event organised and sponsored by the Global Initiative for Chronic Obstructive Lung Disease (GOLD). For more information please visit www.goldcopd.org/wcd-home.html.

What is the best care and how can COPD standards improve?

The state of play in European COPD care, an EFA survey

The second session of the day began with **Sylvia Hartl,** Senior Physician from the Otto Wagner Hospital in Vienna, with a presentation of key findings from the recently released *EFA Book on Minimum Standards of Care for COPD Patients in Europe*. As coordinator for the most recent ERS COPD Audit for standards of care in hospitals, she presented the main related findings. There is a large variation in treatment standards, unacceptably high mortality (11%) and tremendous rate of readmission (35%), she explained. While EFA's first book on COPD in 2009 set a precedent as a patient-centred survey on care, the EFA publication in 2013 focuses on 5 main areas:

1. Prevention
2. Diagnosis
3. Management & Therapy
4. Rehabilitation
5. Alpha-1 Care

With direct costs to European COPD patients ranging from €1,200 – €5,000, she encouraged healthcare systems to take the burden of COPD seriously. She confirmed that the diagnosis of COPD is still occurring too late, guidelines exist but are not always complied with and patients should be obligatorily participants in national discussions of COPD policies or care standards. In addition, she highlighted the need for COPD screening to start earlier, specifically among smokers, when symptoms are visible among people 35 years old and more, during their annual health check-ups. Lastly, access to smoking cessation services and pulmonary rehabilitation was cited as necessitating availability to as many eligible patients as possible. Where this could be linked to employment status, she believed it necessary to remove such restrictions.

Patient driven minimum standards of COPD care for Europe[2]

"Two points are very important and too often overlooked: self-help patient groups and comorbidities."

- Michael Wilken, Chair of EFA's COPD Working Group and COPD patient

Michael Wilken, a COPD patient and representative from EFA's member in Germany, Patientenliga

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[2] Minimum Standards of Care are listed on p. 11 of this event report under **Annex 1**

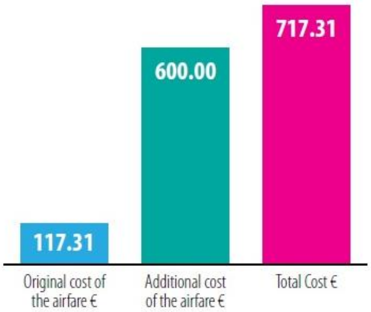
Atemswegserkranguungen e.V., spoke about EFA's minimum standards for COPD care request from the patients' perspective. He stated patients' political goals are not achievable unless they are supported by data. Based on this assertion, he suggested that mortality and prevalence figures should be tracked for COPD in relation to how it impacts the economy. Regret was expressed at how hard facts have not resulted in greater awareness among the public, but he hoped higher standards for patients will imply the achievement of a better quality of life for them. He also discussed the benefits of self-help patient groups, which provide moral support from peers, family and healthcare professionals to improve self-management. He added the failure of a COPD patient to self-manage implies increasing costs and that depressed and frightened patients are more likely to remain in poor health. For this reason, comorbidities were also highlighted as especially important as having an impact on patient's everyday lives. Psychological conditions as common comorbidities were specified as too frequently overlooked.

Three ways to offer help to patients with such conditions were specified:

- When hospitalised, COPD patients should have an evaluation by a psychologist on staff in the facility;
- Self-help patient groups should be used so members can encourage each other to seek help when needed;
- Pulmonologists must bear in mind patient comorbidities like depression when prescribing medicines to avoid medications with side effects.

The event marks EFA's launch of its new book including a list of minimum standards of care, which are included in Annex 1 (p. 11).

Another COPD patient from EFA member association RESPIRA, **Isabel Saraíva**, proceeded to present the EFA booklet *Enabling Air Travel with Oxygen in Europe*. She pointed to the discriminatory policies in place by many European airlines as exemplifying inequalities for patients with respiratory diseases. The discrimination occurs among patients with COPD and other chronic respiratory diseases who sometimes require the use of oxygen tanks to breathe when they travel on aircraft. For both overseas and intercontinental flights, many airlines will charge a flat fare for oxygen use on-board which is usually more expensive than the actual airfare, she said.



Giving the example of the Portuguese national airline TAP, a flight normally costing €117.31 to Brussels from Lisbon costs €717.31 after an additional fee is added as a rate per-bottle of oxygen. In her own experience, she had also encountered airport personnel who were not trained to assist or recognise patients requiring oxygen as passengers with special needs. She encouraged participants at the even to spread the EFA booklet's message to end discrimination and help push for change.

COPD standards of care recommended by physicians and how research can improve them

Representing the International Primary Care Respiratory Group (IPCRG), **Dr. Rupert Jones**, a general practitioner (GP) from the United Kingdom, highlighted the importance of primary care in providing early diagnosis of COPD for patients and in encouraging the self-management of the disease. He explained COPD is a disease without a beginning, as our lungs peak around the age of 25 and get worse over time; for COPD patients, this decline is occurring at a much faster rate and unfortunately it may not be detectable for many until the latest stages of the disease.

Research in primary care is viewed to be helpful for accounting for the missed opportunities to diagnose patients. Education was pointed out as a vital necessity as patients need to be informed of their disease and how to manage it. While there is no universal guarantee, a large number of informed patients who receive rehabilitation will see their quality of life improve. He stated that a "tsunami of costs" resulting from COPD is quickly approaching and better systems with quality care need to be developed to help mitigate its effects.

Patients working with academia and policymakers to inform research

The Patient Input Platform (PIP) for EU health research projects

The final session began with **Dr. Pim de Boer**, PIP coordinator of both the PROactive and U-BIOPRED projects, discussing the involvement of patients in EU health research projects, specifically the Patient Input Platform (PIP) of the PROactive and U-BIOPRED projects. The audience was informed patients should have a complimentary role with research projects in identifying problems and as a part of the operations. As experts living with the disease and the actual effects of their own treatment, they offer opportunities to increase research quality and improve results to facilitate better chances for societal implementation of project results. Moreover, the role of patients in health research must be clearly defined, their needs addressed, and expectations identified, he underlined. He added that project partners must be aware of and flexible with patients as they encounter different problems than researchers which may potentially affect their participation, such as their medical condition itself, their employment status and travelling capacity. For de Boer, patients must be involved from the beginning of a project to be successfully integrated and PROactive along with U-BIOPRED demonstrated this well. The projects provided valuable learning lessons concerning the visibility of patients, language barriers to their involvement and other needs. Ultimately, patient involvement could become routine for research projects if done early enough with the time and investment required, de Boer concluded.

The Role of the Patient in the Innovative Medicines Initiative

The Innovative Medicines Initiative (IMI) is a mechanism enabling private-public partnership for research in healthcare. Senior Scientific Project Manager at IMI, **Nathalie Seigneuret**, explained that while most current research concerns infectious disease, the total percentage for respiratory disease will increase. She informed the audience that 25 patient organisations have been involved in IMI projects across all disease areas and hoped that this number would continue to increase. IMI has the objective of seeing its projects translate science into regulatory and clinical practice, providing innovative approaches for unmet health needs, improved research and development productivity in enterprises and collective intelligence networks, she explained. She confirmed project consortia agree on approaches to intellectual property and related issues before they begin. Patients are seen as important stakeholders to aid projects achieve success, with PROactive and U-BIOPRED as the best examples. With IMI2 approaching, COPD is on the agenda for a number of projects and a new strategic approach will aim for the right prevention and treatment for the right patient at the right time, she concluded.

The real world burden of COPD

"GOLD classifies COPD as common and mostly preventable. We need to focus and limit suffering while enable cost savings"

- Karin Kadenbach, Member of European Parliament

In a presentation of EFA's article "Real world burden of COPD," Member of European Parliament (MEP), **Karin Kadenbach**, explained to the audience why they should expect policymakers in Europe to care more about COPD over time. The age demographic of patients the most affected by COPD is adults in their prime between the ages of 40 – 65 years old. When the patients are forced into retirement or to take additional sick leave days, it implies indirect costs to societies, she added. MEP Kadenbach clarified policymakers *do not* want patients to have the feeling they *must stay in work* if they wish to retire, but rather, their disease should ideally not force them into it. Actions by policymakers at the

European Parliament were also mentioned, such as the commitment from the active ageing initiative of increasing by two years the average healthy lifespan in the EU by 2020.

The EFA study, including a foreword signed by MEPs Liese, Groote, Sieber and Parvanova aimed to describe the real and perceived burden of COPD regarding quality of life, use of healthcare resources and loss of productivity in the workforce, she explained. Results found the real and perceived burden of COPD is lower amongst employed patients. In contrast, COPD patients 'not in paid employment' had a more severe disease, lower quality of life and health state, more exacerbations, higher incidence of comorbidities (including anxiety and depression) and a greater consumption of healthcare resources. She called for policymakers to promote meaningful changes to national COPD care standards and for employers to consider integrating spirometry testing as a requirement for certain employees who are smokers or show symptoms of COPD.

Nicola Bedlington, Executive Director of the European Patients Forum, finished discussion thanking participants for their contributions.

Conclusions and Policy Recommendations

The ECC and EFA acknowledge the significance of Horizon 2020 and its potential effects on both political and scientific research agendas across Europe. In commemorating World COPD Day 2013, guest speakers at the event were able to comment on different ways in which H2020 may be capable of addressing COPD, specific measures which can improve the quality of life for COPD patients across Europe and how the involvement of patients in EU projects can produce better research outcomes. In summary, the ECC and EFA highlighted the need for:

- Increasing efforts in COPD prevention to secure long-term benefits from cost savings and improvements in quality of life;
- Involving patients in EU health research projects and policy from the planning stages and keeping them active through means like the Patient Input Platform (PIP);
- Increases in funding under H2020, to be matched with more ambitious and strategic structuring of research which is aimed towards societal needs
- EU and national policymakers and healthcare systems to consider the patient driven minimum standards of care by EFA as an urgent necessity to prevent the onset of huge societal costs
- Decreasing existing health inequalities by including COPD patients in discussions and planning at the national level within healthcare systems and through European Commission actions where possible to avoid discriminatory practices, as exemplified by airlines.

The ECC and EFA are glad to work together with policymakers and other stakeholders to offer expertise in order to reach the common objective of improving the lives of COPD patients.

Acknowledgements

The ECC and EFA both thank all chairs and speakers for their contributions to their session discussions and attendance to the event. The success of the ECC-EFA World COPD Day 2013 Event would not have been possible without the support of the European Public Health Alliance staff members who supported the organisation of the day.

This report was written by David Brennan, EFA with input from the staff of EFA and the ECC.

Spirometry is the best way to diagnose COPD and should be widely available across Europe.

Further Information

All presentations from the event are available for download as PDF files on the EFA website or from the ECC upon request.

The ECC and EFA joint press release for the event is also available for download from both websites.

Photos from the event are available to the public on the ECC and EFA websites.

Annex 1: Minimum Standards of Care for COPD Patients in Europe

1. Ensure early diagnosis of COPD by using spirometry testing in primary care for current and ex-smokers older than 35 years old;
2. All general practitioners should be adequately educated to administer spirometry testing and interpret the results so as to assure early and accurate diagnosis;
3. Coordination should be increased between primary care, specialists and hospitals to increase efficiency of treatment and quality of life for patients;

4. Smoking cessation services and pulmonary rehabilitation should be made available for all COPD patients in need, regardless of their employment status;
5. Increase the number of centres for COPD care and rehabilitation and ensure there are systematic plans in place for how to avoid exacerbations, consistent follow-ups with patients and intensive up-to-date training on the self-management of the condition;
6. Promote a multidisciplinary approach for the rehabilitation of COPD patients to involve all necessary medical professionals who can improve their quality of life with comorbidity assessments so as to efficiently treat all COPD patients;
7. The participation of COPD patients should be legally embedded in all government decisions or processes directly affecting COPD patient care;
8. Alpha-1 Antitrypsin Deficiency (AATD) testing should be available for infants and pregnant women and augmentation therapy (AT) should be available in all European countries with the possibility for reimbursement;