

Report on the event “Does innovative research for allergy and respiratory diseases in the European Union benefit patients?”



Hosted by: Catherine Stihler and Petru Luhan

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

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The European Union (EU) has invested more than 5.5 billion Euros in innovative research for health during the period 2007-2013 with the aim to develop new health technologies that are evidence-based, promote more efficient and accessible high-quality healthcare services in Europe, provide scientific evidence for effective public health interventions and measures in terms of life styles, work and living conditions, and enhance the EU's role in global health. Special attention has been given to patient safety, identifying the best clinical practice; understanding decision-making in clinical settings in primary and specialised care; and fostering applications of evidence-based medicine and patient empowerment.

The European Federation of Allergy and Airways Diseases Patients's Associations (EFA) organised on Tuesday 17th June 2014 the first stakeholder event of the new European Parliament entitled "Does innovative research for allergy and respiratory disease in the European Union benefit patients?" Co-hosted by Members of the European Parliament (MEP) Catherine Stihler from Socialists and Democrats (S&D) and Petru Luhan from the European People's Party (EPP), the event provided an insight into four EU funded research projects where patients with allergy and respiratory diseases are actively participating. In a context of scarce innovative and research resources, the EU is aiming at meet the challenging health issues in respiratory care. The event genuinely served to reflect the diversity in ongoing research of respiratory medicine, demonstrate the utility of EU-funded projects for patients and how patient involvement can meaningfully shape projects to produce better outcomes that will assist European healthcare systems and improve patients' quality of life in Europe.

The event proposed two sessions where policy-makers from the European Parliament and the Commission gave an overview of the current and future policy developments for innovative research on health related issues. Patients and researchers disseminated the EU-funded projects they lead to the more than 60 participants to the event with specific examples of the patients' role in those projects and the impact of outcomes they are awaiting from the different research initiatives. The first session served as a unique opportunity to learn about the project's results as they were presented for a wide variety of stakeholders, including patients' associations, policy-makers, healthcare professionals, industry, research institutions, technology focused organisations and NGOs. In the second session, these stakeholders could discuss how patient and researchers can work hand in hand on EU funded health projects and ways how outputs from such projects maximise benefits to patients and healthcare systems.

"Investing in health should be one of the main aspects for our drive to raise employment in the EU", MEP Karin Kadenbach

Karin Kadenbach (Austria, Socialists and Democrats) is a member of the Committees on



Karin Kadenbach has been a Member of the European Parliament for S&D since 2009.

Budgetary Control and on Environment, Public Health and Food Safety.¹ Involved in health investments in the past European Parliament legislature (2009-2014), she works to control and ensure that EU money is invested in an effective way. "Investing in health research should benefit people and should be one of the main aspects for our drive to raise employment in the EU", she said in her opening remarks. "Under Horizon 2020, the European Union will spend 80 billion Euros on research and innovation projects and a good part of it will go to research on health. Investing in health could be an incentive for improved health and economics."

“Including patients’ needs, expectations and participation is key for meaningful research”, EFA President Breda Flood



EFA President Breda Flood is a patient with severe asthma.

EFA’s mission is that people with asthma, allergy and chronic obstructive pulmonary disease (COPD) have the right to best quality of care, safe environment and are actively involved in all the decisions influencing their health.ⁱⁱ According to Breda Floodⁱⁱⁱ, “including patients’ needs, expectations and participation is crucial to produce meaningful research.” Over the years EFA has become involved in several EU-funded research projects concerning allergy and respiratory diseases providing patient’s involvement in several dimensions of the research process, but “given the impact of the diseases, we ask for patients’ need to be taken into account while defining policy at EU and national level too”, she pointed out.

3

“The EU has the lead and wants to become a world leader in health technology”, European Commission DG RESEARCH Karim Berkouk

Karim Berkouk^{iv} reflected that the Commission has allocated 5.5 billion Euros to health research, from basic to clinical research for the period 2007-2013. “Thanks to the European Parliament there is an increase of the budget for research in the upcoming years”, he added. The European Commission will soon publish the 2015 work plan seeking to fund projects implying “better understanding of common mechanisms of diseases, new technologies and also bringing personalised medicine towards the clinical setting.” “If we can show the added value of patient involvement we can push for further funding on this”, he explained.



Karim Berkouk is Deputy Head of Unit at the European Commission Directorate-General for Research and Innovation (DG RESEARCH).

What is new in EU research for allergy and respiratory diseases?

“We are gathering data from patients to personalise the treatment of severe asthma”, U-BIOPRED Louise Fleming



Louise Fleming is the U-BIOPRED Pediatric Lead.

U-BIOPRED^v is a project that is currently filling the gaps in asthma knowledge. “Asthma is a very common disease which significantly impacts daily life, but the pipeline for developing new therapies is slow”, explained Louise Fleming^{vi}. One of the outcomes of U-BIOPRED will be the generation of an asthma handprint from the characteristics, features and symptoms collected from over a thousand patients with asthma and healthy volunteers. In collaboration with other consortium partners, U-BIOPRED counts on a Patient Input Platform (PIP), formed by patient volunteers who collectively participate to the project’s development and activities. Their insights and contributions to the different project work packages have made a difference. The PIP chair, David Supple, co-presented U-BIOPRED from his perspective as a carer of a son with severe asthma and hoped that “the handprints will lead us

to better understand the different mechanisms present in patients.” He added that in this context, patient involvement can serve to influence the research decisions and that researchers are trying to “facilitate patient participation with revised questionnaires and easier recruitment procedures.”

“With all these innovative projects we will redefine allergy and respiratory diseases for better treatments”, MeDALL Charles Auffray

MeDALL^{vii} is an EU project aiming to improve early diagnosis and prevention of allergy. “Over two decades we have collected information from more than 43,000 children who are now between 4 and 18 years of age. This treasure is now combined with biological and functional data to harmonise the definition of the allergy phenotypes and identify the mechanisms of their development”, explained Charles Auffray^{viii}. Patient involvement is crucial to better understand diseases so “today we are advocating for participatory medicine as a driver for an integration



Charles Auffray (right), from the University of Lyon (France) participates in MeDALL with Per-Åke Wecksell (left), EFA Board Secretary (Sweden).

between biology, medicine, engineering and computer sciences”, he added. With scientific research due to wrap up in the coming year, the MeDALL consortium partners are excited to reveal their progress and how they can be used for real-life improvement of allergy conditions. Per-Åke Wecksell, allergy patient expert and EFA’s Board Secretary, has participated in this project since 2010. “As a patient you always think: Why me? What can I do? Well, patients need participation and expectations”, he stated. “This project seeks to answer our questions on allergy. Thanks to MeDALL we will help create a template for national allergy management programmes in Europe”, he acknowledged.

“We can soon predict the asthma and COPD patient’s response to treatments before the intervention”, AirPROM Chris Brightling

AirPROM^{ix} is a technology project that is creating a model of the human lung to virtually anticipate the results of treatments in patients with asthma or COPD. “We want to know what we need to measure from patients and why some people do not respond to treatments. To achieve this, we have to go to a patient specific level and move towards personalized care. While working with patients, not only we gather data to better control diseases, but we also have a good opportunity to ask patients about their opinions”, explained Chris Brightling^x. Although AirPROM is a very technical project, patients play a key role both as participants in clinical trials and as consortium partners helping to disseminate project information. One such patient involved in a clinical trial, Gay Bottomley, co-presented on her experience with the project, stating that ultimately “this is about people. As a patient, it is a good thing to be involved in research projects because we can see what and why medicines are out there for us.” Ms Bottomley added patients can also learn ways they can improve their quality of life, specifically through coming into closer contact with the practitioners participating in the project.



Chris Brightling (left) AirPROM’s Project Coordinator with Gay Bottomley (right), a severe asthma patient.

“We need to help people with asthma to manage their asthma”, EARIP Samantha Walker



Samantha Walker, from Asthma UK, is EARIP's Project Coordinator.

EARIP^{xi} is an EU funded project seeking to boost innovation in asthma within the European Union. “We are focused on the societal struggles that belong to asthma patients”, stressed Samantha Walker^{xii} from the patient association, and EFA member, Asthma UK. For example, “there is not a clear test for asthma, so we want to define how much it will cost to develop a diagnostic tool for asthma and help asthma patients to stay on top of their symptoms and identify early warning signs.” EARIP ultimately seeks to establish a common research agenda for asthma in Europe over the coming years in order to ensure that treatment of asthma progresses as efficiently as possible to assist people with asthma.

5

Impact of project outcomes and patients' involvement in EU research

The first panel session, moderated by David Supple, sought to address the crucial question of how the research projects for allergy, asthma and COPD could make a difference in the lives of patients. While it was acknowledged that lessons have been learned from previous projects that lacked tangible results, participants shared their optimism that an increase of funding to projects specifically addressing respiratory disease would be possible in coming years.

“People living with chronic diseases need to continue to be part of society”, European Commission DG SANCO Michael Hübel

Although healthcare systems and social investment rely on EU national budgets, the European Commission is working to improve public health across the 28 Member States, not only by legislating on risk factors related to food allergies and tobacco, but also through its work on chronic diseases. “The European Commission has just launched the joint action on chronic diseases to look at good practices on co-morbidities, diabetes and health promotion, among others. Health and social systems have to adapt to the chronic diseases challenge and here strengthening and empowering patients is one of the keys in this context”, explained Michael Hübel. “We are working to find approaches that impact major diseases, since patients do and will not necessarily fit in the boxes the health system provides now; joint actions with Member States towards chronic disease is one approach in this direction”, he stressed. It was further acknowledged that while the EU serves its role by advising, coordinating and creating legislative frameworks, organisations like EFA may contribute in synthesising actions at the national level through the sharing of best practices and other activities.



Michael Hübel is Head of Unit at European Commission Directorate-General for Health and Consumer (DG SANCO).

“We are at an age of partnership between patients, researchers and healthcare professionals”, IPCRG Mike Thomas

For healthcare systems, the role of primary care can be crucial as the first point of contact for patients. Whereas traditionally research projects have had limited representation of primary care, projects like U-BIOPRED demonstrate a shift towards their inclusion. Furthermore, primary care has an interest to see research produce benefits for a broader range of patients. As reflected



Mike Thomas is Chair of Research at the International Primary Care Respiratory Group (IPCRG).

by Mike Thomas from the International Primary Care Respiratory Group, “in the past the research focus was on the five percent of patients whose needs were incredibly important, however a huge amount of patients do not come to hospitals and are only looked after by family physicians.” For Professor Thomas, “our concepts of diseases are constantly evolving and are driven by real life interaction with patients who each have an individual set of needs.” The result is that today we are moving towards a team-based approach requiring a broader range of expertise and collaboration, which should be reflected into both EU research processes and their consortia.

“Respiratory diseases are illnesses of the poor, and disaffected, who need to be included in research”, ELF Dan Smyth

Diving into deeper and more political topics, Dan Smyth, the Chair-elect of the European Lung Foundation, pointed towards health inequalities as a burning issue which is not just limited to national level healthcare systems. In fact, for Mr. Smyth, European level research is representative only if it engages with marginalised peoples of society and people from less wealthy geographic regions. Interested in gathering data on respiratory diseases from all over the EU and furthering involvement of stakeholders from Eastern Europe in EU-funded research, Dan Smyth believes that it will not only be beneficial in terms of public health (as the population is younger in the East with a higher use of tobacco, including exposure of children to tobacco smoke) but also economically as it would reduce the burden of chronic diseases in the long run. “There are certain communities out there we do not engage in and talk to, even though they are a large part of the groups that have these diseases. There needs to be an output mechanism that reflects all opinions”, he stated.



Dan Smith is Chair-elect of the European Lung Foundation (ELF).



Zoltan Massay-Kosubek is Policy Coordinator at the European Public Health Alliance (EPHA).

“Research priorities indicate political importance of respiratory diseases like COPD or allergy”, EPHA Zoltán Massay-Kosubek

For Zoltán Massay-Kosubek, joint research actions involving the European Institutions and Member States can significantly benefit patients. Respiratory diseases have a strong health inequalities aspect: “Evidence shows that vulnerable people have poorer health outcomes. It is unacceptable to have people suffering from respiratory diseases due to their financial situation and this requires attention.” Patient involvement would be key in this sense as “research priorities not only produce evidence but also indicate political importance within research. Research

dedicated to respiratory diseases like COPD or allergy should be in line with their societal impacts”. By reflecting to the political dimension of the debate, tobacco remains the most important risk factor for respiratory diseases. In the view of Mr. Massay-Kosubek, the new tobacco products directive (TPD) could reduce the amount of smokers within the EU. Plain packaging was identified as a potential policy measure that could serve as a critical step forward in decreasing chronic respiratory diseases and the new TPD allows member states to adopt that evidence-based policy. By including additional text warning on tobacco packages on the risk to develop COPD, asthma and other respiratory diseases, future generations may be convinced to change lifestyle and diminish future costs of these diseases for European societies.

In the second panel session of the event, patient participation in EU-funded health research projects became the center of attention. Scott Wagers from BioSci Consulting, the scientific coordinator of the U-BIOPRED project, asked panelists whether they believed the creation of a European Patient Input Platform (EPIP) can address a deficits in patient participation in research.



Camille Bullot is Membership Officer at the European Patients' Forum (EPF).

“Patients should be much more involved in influencing the research agenda than they currently are”, EPF Camille Bullot

Representing the European Patient's Forum, Camille Bullot described the EUPATI Project led by EPF, which seeks to educate patients about medicines research and development to increase the capacities and capabilities of well-informed patients to be effective advocates in medical research. “Patient involvement is crucial to ensure that the research is relevant to patient's needs and to obtain an accurate risk-benefit assessments”, she stated. Camille Bullot commented on the importance to ensure patient participation in the development, structuring and evaluation of clinical trials as a moral right. “They should also be much more involved in influencing the research agenda than they currently are”, she stressed, “there are still many gaps between patients' priorities and what is actually being studied”.

“Patient Input Platform is a workable model for health research”, U-BIOPRED David Supple

During the discussion, panelists agreed that patient involvement will be increasingly crucial for healthcare EU-funded research projects. Moreover, their participation in innovative research projects could help finding common ground in establishing research priorities between patients, researchers and medical professionals. Panelists confirmed that the European Commission could play a role in the facilitation of common understanding between stakeholders, but more importantly, it could also conduct a review on the patients' contribution to projects and how they can be best involved.

Within the context of the U-BIOPRED project, the Patient Input Platform (PIP) ensures patients with a complimentary role in the project, as they can help identifying problems and



David Supple is the chair of the Patient Input Platform (PIP) within U-BIOPRED.

serve as experts living with asthma. Yet the individual experience of a disease once again stresses the importance of health inequalities, as marginalised populations are certainly experiencing their diseases and treatments much differently than those with better access to care. The concept of including a PIP was perceived to serve as a potential vehicle for engaging with these groups and as a mechanism to reflect the widest range of patient involvement possible.

“We need new technology to access the patients that want to be informed and involved”, MEP Catherine Stihler

The event's host, MEP Catherine Stihler^{xiii} stressed that the EPIP could be “a step for sharing best practices” and it was acknowledged in terms of outcomes and costs for European health services that by putting patients first, research can focus on improving the quality of life for patients from the outset. “Patients have the right to be involved in all decisions influencing their

health. Their expertise and vision should always be requested and taken into account, as they know better than others what it means to live with the disease and which kind of risks they are willing to take to have benefits in exchange”, summarised MEP Catherine Stihler. The panel participants acknowledged that in addressing challenges in disease and poverty, attempting to draw together EU communities, the future EU projects, and perhaps an EPIP itself, may need to go out into the communities – especially in the poorer and disconnected areas – to attract more equitable interest and participation.



Catherine Stihler has been a Member of the European Parliament for S&D since 2009.

Conclusions and policy recommendations

There is a common understanding among European Union policy-makers, academia and patients that working together across the Member States, creating multidisciplinary research teams and involving patients ranging from all sort of conditions is key to produce meaningful results. The European Parliament was the perfect setting to bring together policy-makers, academia, medical professionals, patients and carers to analyse how the path shown by the EU institutions is matching realities on the ground. All speakers were unanimous acknowledging the EU's willingness to foster and support innovative research in a more flexible and broader way; scientific research that would take on board the societal elements that affect patients and would seek prevention, care and outcomes that could fit the variety of health systems across Europe.

Allergies and respiratory diseases remain a burden for our society and productivity in Europe. Participants highlighted how research initiatives could move further from the “cause” perspective towards a “ready-to be implemented” research that could be focused on the consequences of chronic diseases to serve patients. Innovative research provides a ways in which a broad range of stakeholders can work together to improve the lives of patients and improve healthcare systems. Among the ideas for improvement flagged by the participants to this event we can find the following recommendations:

1. **Foster multi-stakeholder research to ensure tangible outcomes for patients:** EU funded research results are likely to benefit healthcare and therefore patients only if funding targets specific topics affecting systems and patients at all levels.
2. **Set research agendas based on patients' needs:** panelists referred to the need of including patients' disease representation (gravity of conditions) and social representation (geographical, income, gender differences) to ensure project results provide insights of diseases from an EU perspective. Involving patients in EU funded health research can provide meaningful results to inform decisions makers. A way of doing this could be to integrate Patient Input Platforms (PIP) in each project.
3. **Research should also tackle the leading cause of respiratory diseases:** panelists recognized that one perfect example of a way to improve respiratory health across Europe would be to tackle tobacco use and consider research approaches addressing the issues, such as smoking cessation.

Acknowledgements and further information

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Photos of the event are available here: <http://www.efanet.org/ep-event/>

ⁱ Karin Kadenbach official website: <http://www.karinkadenbach.at/>

ⁱⁱ EFA: <http://www.efanet.org/>, Twitter: https://twitter.com/EFA_Patients and Facebook: <http://www.facebook.com/EFAPatients>

ⁱⁱⁱ Breda Flood presentation: www.efanet.org/wp-content/uploads/2014/06/EFA-Projects-Speaker-Breda-Flood_EP-20140617.ppt

^{iv} Karim Berkouk presentation: www.efanet.org/wp-content/uploads/2014/06/EC-DG-RESEARCH-Speaker-Karim-Berkouk_EP-20140617.pptx

^v U-BIOPRED: <http://www.europeanlung.org/en/projects-and-research/projects/u-biopred/home>

^{vi} Louise Fleming presentation: www.efanet.org/wp-content/uploads/2014/06/U-BIOPRED-Speaker-Louise-Fleming_EP-20140617.pptx

^{vii} MeDALL: <http://medall-fp7.eu/>

^{viii} Charles Auffray presentation: www.efanet.org/wp-content/uploads/2014/06/MeDALL-Speakers-Charley-Auffrey-Per-Ake-Wecksell_EP-20140617.ppt

^{ix} AirPROM: <http://www.europeanlung.org/en/projects-and-research/projects/airprom/home>

^x Chris Brighting presentation: www.efanet.org/wp-content/uploads/2014/06/AirPROM-Speaker-Chris-Brightling_EP-20140617.pptx

^{xi} EARIP: <http://earip.eu/>

^{xii} Samantha Walker presentation: www.efanet.org/wp-content/uploads/2014/06/EARIP-Speaker-Samantha-Walkers_EP-20140617.ppt

^{xiii} Catherine Stihler website: <http://www.cstihlermep.com/news.php#button642>