



“We know how to curve down asthma in Europe: lessons from national programmes”

EARIP STAKEHOLDER WORKSHOP

Brussels | September 15, 2015

Introduction

In Europe, 10 million people under the age of 45 have been diagnosed with asthma and it is the most common non-communicable disease among children. The economic burden on European countries is also substantial, with direct costs of €11 billion and indirect costs of €14 billion. In 2013, the World Health Organisation (WHO) estimated that 5.2 billion disability adjusted life years (DALYs) are lost each year in the EU as a result of asthma.

The increasing prevalence of asthma, its costly burden, as well as clear gaps in research were the main drivers behind the creation of the European Asthma Research and Innovation Partnership (EARIP). Through coordinated pan-European research activities with world leading asthma researchers, it aims to reduce asthma deaths and hospital admission rates, speed up the discovery of new treatments and improve daily life for people with asthma, uniting all stakeholders around a common goal.

The European Federation of Allergy and Airways Diseases Patients' Associations (EFA), on behalf of EARIP, leads a work package aimed at contributing to the development of improved and efficient health and care systems for asthma in Europe. As part of this activity EFA organised a Stakeholder Workshop on the 15th of September 2015 at the European Parliament.



Hosted by Member of the European Parliament Catherine Stihler (United Kingdom, Progressive Alliance of Socialists and Democrats) was entitled: “We know how to curve down asthma in Europe: Lessons from national programmes”. MEP Stihler is vice-chair of the Committee on the Internal Market and Consumer Protection and has a clear interest in tackling the burden of chronic disease.

The event aimed to inform policy-makers and the public of the EARIP project findings on national and regional asthma programmes in Europe, building on the results of the literature review “National and regional asthma programmes in Europe: a systematic review”¹, and gain support for the implementation of a European Research and Innovation Partnership as a mechanism for realising better asthma management in Europe.

The workshop included two plenary sessions exploring existing asthma management programmes in Europe, including presentations on how these can be improved and then shared among European countries. This was followed by a dynamic panel discussion addressing the questions “What is needed to achieve change in the European Union? How to realise the vision of the European Innovation Partnership in Asthma?” This served as a unique opportunity to explore different viewpoints on how to achieve cost-effective, innovative and inclusive healthcare system change in asthma through a Research and Innovation Partnership.

¹ Selroos, O, Kupczyk, M, Kuna, P, Lacwik, P, Bousquet, J, Brennan, D, Palkonen, S, Contreras, J, FitzGerald, M, Hedlin, G, Johnston, S, Louis, R, Metcalf, L, Walker, S, Moreno-Galdó, A, Papadopoulos, N, Rosado-Pinto, J, Powell, P, Haahtela, T. National and regional asthma programmes in Europe. *European Respiratory Review*, [Online]. 2015; 24: 474-483. Available at: <http://err.ersjournals.com/content/24/137/474.full> [Accessed 15 October 2015].

ASTHMA, A EUROPEAN PROBLEM THAT NEEDS A EUROPEAN ANSWER

Collaboration among experts that represent a broad range of expertise is key to addressing the gaps in asthma research, and MEP Stihler thanked EFA and Asthma UK for uniting the various relevant stakeholders for this meeting

She underlined the prevalence of asthma in Europe, its economic and societal burden for Member States, patients and families. She emphasised that asthma, as a European problem, deserves a European answer. Therefore the European Parliament, which lies at the heart of EU Policy-making, was the perfect setting to bring together policy-makers, academia, medical professionals, patients and carers for this Stakeholder Workshop. The location was also fitting since EARIP, as an EU-funded research project, should communicate and promote its results at the level of EU institutions.



“Asthma is a public health issue and not a disease issue”

Catherine Stihler, MEP

What have we learned from national asthma programmes?

NATIONAL ASTHMA PROGRAMMES CAN PREVENT ASTHMA DEATHS

With the purpose of uniting Europe with a common asthma agenda, a systematic review of existing literature on regional and national asthma management programmes was conducted.

The review showcased the success of asthma management programmes in Finland, Portugal and Poland in reducing the burden of asthma through relatively simple measures and the potential to achieve similar results in the Netherlands, France, Ireland, Italy and Turkey. With reductions in asthma associated deaths and the cost per patient, disability pensions and costs and hospital admission rates, the Finnish programme achieved cost savings of €300 million per annum.

Early diagnosis, guided-self management, a multidisciplinary approach and active treatment are key factors in reducing hospital admission rates and avoiding asthma deaths. Guided self-management and the promotion of asthma health and control, rather than the disease, is a necessity. This helps to ensure that all patients and their healthcare professionals are equipped to control and manage asthma. Professional, patient and public education in asthma are key success factors.



“We need a broad consensus, an action focus on asthma patients and especially on severe asthma to stop exacerbations and attacks.

A community problem needs community solutions
[T.Haahtela]”

Dr Olof Selroos

PATIENT SAFETY AND QUALITY OF CARE IS AN EU PRIORITY

Dr Aurélien Perez presented the vision of the Healthcare Systems Unit of the European Commission's Directorate-General of Health and Food Safety (DG SANTE). He agreed that with appropriate asthma management programmes quality of life for patients and for their carers can be improved.

Even though the power of the EU is restricted in the field of health, special attention was given by the European Commission to patients' safety and quality of care. Some of the EU actions in this field are the set-up of an EU expert group and a European network on patient safety and quality of care. Both groups promote the exchange of knowledge, best practices, and viewpoints by representatives of the European medical community.

The European Commission also provides support through EU-funded projects, such as the [EMPATHiE project](#)², which focuses on patient empowerment in the management of chronic diseases. There is also an upcoming pilot project on self-care systems for chronic diseases and an ongoing study on costs of unsafe care and cost-effectiveness of patient safety programmes.



“The European Parliament and the Member States show a strong interest to do more in the field of Patient Safety and Quality of Care”

Dr Aurélien Perez

According to priorities identified by the Council of the EU, and expressed in the Council conclusions on patient safety and quality of care dated 1st of December 2014, a framework for sustainable EU collaboration on patient safety and quality of care by EU Member States is needed. The European Parliament report “Safer healthcare in Europe”, which was adopted on the 19th of May 2015, contributes to this by calling on the Commission and EU Member States to develop a coordinated and sustainable EU strategy for patient safety.

² <http://www.eu-patient.eu/whatwedo/Projects/EMPATHiE/>

QUALITY OF LIFE IN ASTHMA THROUGH CHRONIC OPTIMISM AND EMPATHY

Martine Puhl, patient representative and member of EARIP's Patient Advisory Group (PAG), brought the patient perspective to the meeting and highlighted the fact that Asthma patients do not just represent a disease; they are people trying to make their way through life as best they can.



“When I visit my doctor’s office, I am defined by my condition, the medication I take, my lung capacity. But that is not me, I am more than a patient. Chronic Diseases require chronic optimism.”

Martine Puhl

She explained why patients have an interest in contributing to research and elaborated on the added value that patient-researcher collaboration can bring. There are about 30 million asthma patients in Europe, and all of them have particular needs. There is no one solution for all. Involving patients in research and policymaking can help address the variety of individual patient needs.

Patients can face obstacles related to becoming involved in research, e.g. their own workload outside of the project. Therefore, she added:

“You need a strong patient organisation that can enable patients’ active involvement, so that the needs of the patients can be voiced in the project.”

Martine Puhl

Developing better asthma programmes across Europe

SCALING UP ASTHMA TREATMENT IN EUROPE

Dr Samantha Walker presented on the European Asthma Research & Innovation Partnership (EARIP), a European Commission supported research initiative which is identifying a comprehensive roadmap for asthma research and innovation in Europe for the next two decades. She pointed out that the review of existing national and regional asthma management programmes in Europe, presented during the meeting, showcases the demonstrable success of healthcare systems when they prioritise and invest in asthma across the system. To date only a few results from these programme experiences have been published. However, even though Healthcare systems on asthma differ from one country to the next all face similar barriers and have similar needs and may require similar solutions.

The European Asthma Research & Innovation Partnership hopes to influence the provision of high-quality and affordable services for asthma care in Europe. Through the sharing of best practices in Europe and the implementation thereof in the different EU Member States, EARIP hopes to scale up asthma care. EARIP is working towards this with strong leadership and coordination by linking up all involved actors.

The organisation of meetings and workshops with relevant stakeholders contributes to the identification of knowledge gaps and the health system changes needed in order to build the framework for a European Innovation Partnership for Asthma. If successful this framework would unite people with an interest in asthma and asthma research behind a common goal and eventually solve the asthma problem in Europe.



“Translational programmes, such as EARIP, are needed to enable the sharing of best practices in healthcare systems across Europe and their implementation”

Dr Samantha Walker

BIG DATA FOR BIG HELP IN ASTHMA

There is a large variance in the way asthma impacts European countries. Asthma mortality hits vulnerable groups (with low socioeconomic status) the most. The social life and the quality of life of the people affected need to get more attention, as well as tools for guided self-management in asthma. “If a patient knows very well how to manage his or herself in his or her own situation it does prevent hospitalisation. Professor Ildikó Horváth”

There are significant existing gaps in asthma prevention and self-management in Europe, such as the introduction of appropriate surveillance systems, data integration between environmental factors and asthma attacks, the access to cost-effective medicines and the application of standards and accessibility of care at different levels of the health care system. Fostering collaboration between European countries in the sharing of existing knowledge and best practices can address the existing gaps and enable the development of innovative solutions in the field of asthma research.



“A roadmap needs to be developed, to scale up asthma prevention, treatment and care in the EU.”

Dr Ildiko Horváth

EARIP can contribute to this endeavour by enabling knowledge transfer among patients and professionals, more information about patient needs and a multidisciplinary approach to bridge the existing gaps.

MOBILISING TOWARDS EVIDENCE BASED SYSTEM CHANGE IN EUROPE

Following the presentations of the plenary session, panel members, moderated by EARIP Project Coordinator Samantha Walker, engaged in a dynamic discussion with participants on how a European Research and Innovation Partnership in Asthma can contribute to healthcare system change in Europe.

Dr Samantha Walker, Deputy Chief Executive and Executive Director for Research & Policy with Asthma UK, pointed out that one of the key success factors of the Finnish programme is

the senior support and acceptance of the idea. It is also important for EARIP to mobilise the evidence throughout the EU so that other countries can learn from it.

Zoltán Massay-Kosubek from the **European Public Health Alliance (EPHA)** underlined that Asthma is a public health issue and focused on three points: EARIP's ambition for healthcare system change is evidence-based, but the health arguments should be translated into economic terms, as our EU decision making procedure is still economically focused. He questioned, how could EU policy-makers vision more jobs and growth with an unhealthy population? Secondly, the EU can play an important role in prevention, by focusing on risk factors for asthma (e.g. smoking, air pollution) which are risk factors for other diseases, too (e.g. lung cancer, COPD, cardiovascular diseases), where the EU has competence (e.g. the tobacco products directive [TPD] or the national Emissions Ceilings directive [NEC]).



Finally, he stressed that even in the field of healthcare where the EU's competence is limited, partnerships and sharing of best practices among EU Member States would be beneficial. He furthermore expressed interest to support EARIP.



Dr Sofia Ribeiro from the **World Health Organisation (WHO)** supported the focus on prevention, and relevant risk factors (such as air pollution, smoking) as brought forward by Zoltán Massay-Kosubek. She also stressed the importance of health determinants (including lifestyle), as this has also a very important role in the manifestation of the condition. She furthermore framed asthma as one of the chronic respiratory diseases that should be tackled together by a joint approach, given the difficult economic situation we are in today.

Susanna Palkonen, **Director of the European Federation of Allergy and Airways Diseases Patients' Associations (EFA)**, brought the patient perspective. She raised the point that the key to successful asthma management programmes is, and has been, gathering all relevant stakeholders in the field, attributing clear roles to all different actors: policy makers, all healthcare professionals, including not just doctors, but also nurses and pharmacists, patient groups and industry.

“Let’s take what we learned from the EARIP literature review: ‘Hit asthma early, hit hard’, but with chronic optimism and empathy. This is what EARIP represents to us.”

Susanna Palkonen



Dr Terje Peetso, represented the European Commission’s Directorate-General for Communications Networks, Content and Technology (DG CONNECT). She pointed out that health literacy and access to information are important for patient empowerment. She also suggested that we learn from the existing partnerships e.g. the European Innovation Partnership on Active and Healthy Ageing that contributes to healthcare system change bringing together actors who do not usually cooperate in this field.

Dr Ildiko Horváth from the European Respiratory Society (ERS) raised the point that even though severe asthma is not a high priority on the agenda of EU Member States, a lot more needs to be done in this field. National experts from EU Member States need to examine the steps required in their country’s day-to-day practice in order to reduce asthma deaths in Europe.

From existing asthma management practices we can derive the evidence-based key performance indicators which will be fundamental to the implementation of successful asthma management programmes in Europe.

Dr Samantha Walker concluded the meeting with the message that consensus between the different stakeholders is needed, and this is something EARIP will attempt to do as part of the overall project objectives.

Conclusions

Asthma is one of the major non-communicable diseases, which is still often underdiagnosed and undertreated. Over 300 million people suffer from asthma worldwide, and 30 million of them are living in Europe.

During the discussion there was a common consensus among panellists that a change of mind-set is required in the EU Member States in order to effectively promote asthma prevention and care.

Conclusions from the workshop and panel sessions:

National/regional asthma management programmes are a workable model to alleviate the (financial) burden of asthma on the EU (e.g. all programmes resulted in a reduction of asthma-caused hospitalisation rates) and the individual burden on patients and their families.

Foster multi-stakeholder collaboration: EARIP is creating a network of actors in the field of asthma prevention, care and research. This partnership has the opportunity to bring together relevant stakeholders in the field, typical as well as atypical actors, so that different viewpoints and contributions at all levels of society are harnessed.

A change of mind-set in the EU Member States is needed for the promotion of asthma care and prevention; however changing the status quo is difficult. Senior support from national key opinion leaders and policy-makers will be required in order to achieve successful implementation of asthma management programmes in the EU Member States.

Integration of asthma prevention is key. This must be tailored to the specific country needs and with an emphasis on lifestyle change. Innovations in mobile health technology can support this action. Health literacy (guided self-management) will enable patients to be more informed about their condition and to make informed choices.

NEXT STEPS

The outcomes of this workshop, together with the outcome of the literature review “National and Regional asthma Programmes in Europe: a systematic review” will be discussed in the **EARIP Expert workshop**, which will be held in **London on the 21st of October**, and this will feed into the development of recommendations on effective measures for healthcare system change.