



The Rights & Needs of Older Patients – *case study of older patients with respiratory disease*

Patient perspective

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EFA

- 32 member associations in 22 countries, in which over 500.000 patients/carers
- Representing people with allergy, asthma & chronic obstructive pulmonary disease COPD
- **Vision:** To become the leading reference point for people with allergy, asthma and COPD
- **Mission:** making Europe a place where people with allergy, asthma and COPD
 - have the right to best quality of care & safe environment,
 - live uncompromised lives and
 - are actively involved in all decisions influencing their health



For patients

- Provides transparent access to information and educational tools in patient-friendly language
- Provides opportunities to participate actively in projects

For member organisations

- Actively communicates with member organizations identifying their needs
- Develops projects to meet these needs

For Healthcare Professionals & Scientists

- Facilitates communication in patient-friendly language focusing on patient needs
- Develops and promotes long term partnership on equal level
- Develops training and educational projects
- Ensures active participation of patients in all decisions regarding their wellbeing

For Policy makers

- Acts as liaison between people with allergy, asthma and COPD and EU policy-makers
- Negotiates to raise standards of care, environment and research
- Communicates and updates about patient needs

For NGOs & industry

- Develops and promotes long term partnership
- Ensures well defined conditions of partnership

20

creating
years

Allergy, Asthma & COPD in Europe

- 4 to 10 percent adults have COPD, 44 million
- Total financial burden €102 billion and increasing
- Growing social burden: 21 %of COPD patients are severely disabled
- “COPD is predicted to be the third leading cause of death in 2030”, WHO
- 80 million people have allergy
- One person every hour dies from severe asthma in Western world
- Asthma is the most common chronic disease in children, 1 in 4 children have allergy



“On a bad day I feel like I’m drowning and I can’t reach the surface of the water and I am going to burst, yet a tiny, tiny bit of air keeps me alive. It’s very scary - I feel like I’m living with a time bomb and if I have a bad attack I say to myself: Is this the one that will kill me?”



Catherine Tunnicliffe U.K.

“I changed job a little while ago, but after only a few days, I had to take time off sick because of my asthma. This caused bad feeling at work and made me feel very defeated.”



Genoveva Villar SPAIN

“I was diagnosed with COPD 2006, after having pneumonia. The doctors tell me it is the smoking, even when I quit 17 years ago.

I have had to quit my job, sports and I am on 80% disability pension. My neighbour used to always greet me, but now hides inside when I am on oxygen.

I continue to be active in voluntary work as a coach in bicycle racing school, but without bike now.”

COPD Patient, 58, France

Some of the issues for people with allergy & respiratory diseases:

Managing & recovering exacerbations

Dealing with new environments indoors & out

Tiredness

Lack of information and education

Side-effects of medication & fear of them

Always being prepared

Vicious circle of flare ups

Cost of medication

Doing exercise & enjoying sports

BREATHLESSNESS

Avoiding triggers

Always being prepared

ITCHING

Night awakenings

Self-image

Work/school absence

Choice of occupation

Stigma

Fear of dying

Access to correct diagnosis
& comprehensive care

Always taking care

Finding products that do not induce allergy

Social isolation

Problems of intimacy

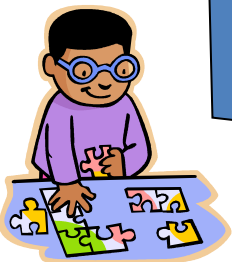
Self-esteem

Stigma

Irritability

Pregnancy

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- Prevention
- Smoking cessation
- Early diagnosis
- Health care
- Social support
- Food labelling
- Medical devices
- Managing co-morbidities

**My
TREATMENT**

- Medicines
- Rehabilitation
- Reimbursement
- Information
- Education
- Adherence, concordance
- Information & Communication technology - eHealth

**My
ENVIRONMENT**

- Indoor Air
- Outdoor Air
- Chemicals



**My
PARTICIPATION**

- Treatment
- Society
- Health, Environment & Research Policy

**RESEARCH
IN**

- Prevention
- Care
- Medicines

- Quality of Life
- Finding the cure

Older Patients

Working age -> high risk -> premature interruption of working life

-> Consequences:

- financial difficulty
- isolation, loss of social network
- feeling useless
- loss of integrity & dignity
- depression
- inactivity
- carers challenges, wellbeing and working life

Work is life but life is not work.

More life into years – More years into life



Older Patients

Solutions

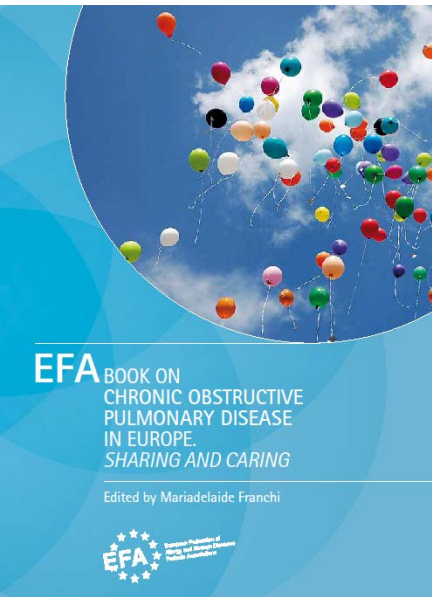
- Innovative work solutions
- Homecare support – eHealth
- Patient centred care - Personalised medicine
- Health & social care integrated
- Infrastructure & society supporting mobility & activity

NEW THINKING!

- Older people including those with chronic disease are a resource – not burden
- Focus on what can do instead of what cannot
- Army of potential volunteers
- Prevention and care ambassadors & tutors!



EFA in action: From Patients to Policy Makers



EFA COPD Project

- Patients as researchers, partnership with healthcare professionals
- Concrete findings made in collaboration with all – EFA Book on COPD in Europe, 12 countries featured
- Patient advocacy agenda advanced: Call to Action on COPD at European Parliament
- Follow-up project 2011 – stakeholder workshops on the Call to Action at the EP in preparation of formal policy initiative (29 June & 9 November)
- People with COPD are ‘older patients’ & have co-morbidities: heart disease, diabetes etc


EFA Respiratory Allergy Awareness project – 4 year awareness and action programme

- EFA Book on Respiratory Allergy
- 15 countries
- 22 November Launch event & Call to Action at the EP
- Partnership with healthcare professionals



EFA in action: Patient Involvement in Research

 Innovative Medicines Initiative: UBIOPRED Unbiased biomarkers in the development of severe respiratory disease (*asthma*)

 7th Framework Programme for Research FP7: MeDall Investigation of the mechanisms of initiation of allergic response, genetic predisposition, biomarkers & identification of targets for therapy

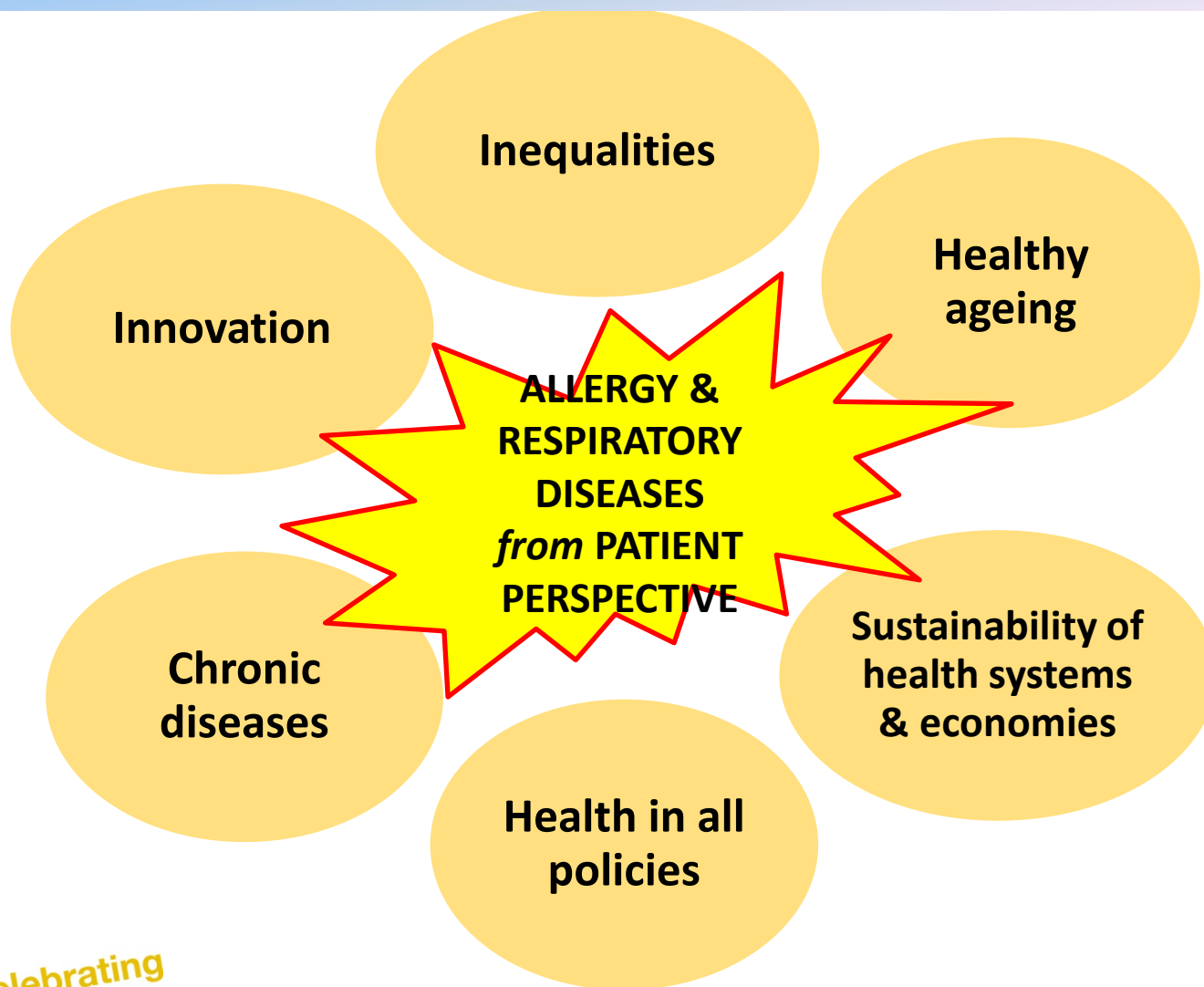
 FP7: AIRPROM Airway Disease PRedicting Outcomes through Patient Specific Computational Modeling

 Public Health Programme: Health Based Ventilation Guidelines for Europe



**Patient role: input to the research, ethics, communication, dissemination, recruitment
-> specific needs of older patients with co-morbidities & severe disease**

Polish Presidency & Integration



Polish Presidency & Integration

- Bridging the health & access to health care & prevention gap between individuals, regions, countries, continents, diseases
- From fragmentation of and gap between policy & action into:
 - EU strategy/action plan on allergy & respiratory diseases that facilitates comprehensive patient-centred national programmes
- Chronic diseases agenda with workstreams on the different diseases



Polish Presidency & Integration

Respiratory journey starts from
mother's womb or before from the very
first cell & ends with the last breath &
we are not all equal

Without breathing there is no life



EFA EU Policy goal

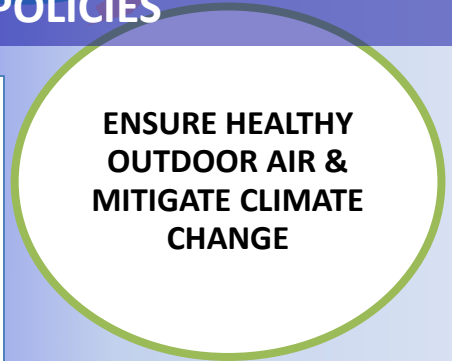


ALLERGY and RESPIRATORY DISEASES in ALL POLICIES



EU role: European strategy & programme on allergy, asthma & COPD respiratory diseases

Support for 2nd EU Environment & Health Action Plan



Work with all stakeholders

