EFA

European Federation of Allergy and Airways Diseases Patients' Associations

Monitoring and communication devices: *the perspective of the patients*

Giuseppe De Carlo

EFA Project Manager

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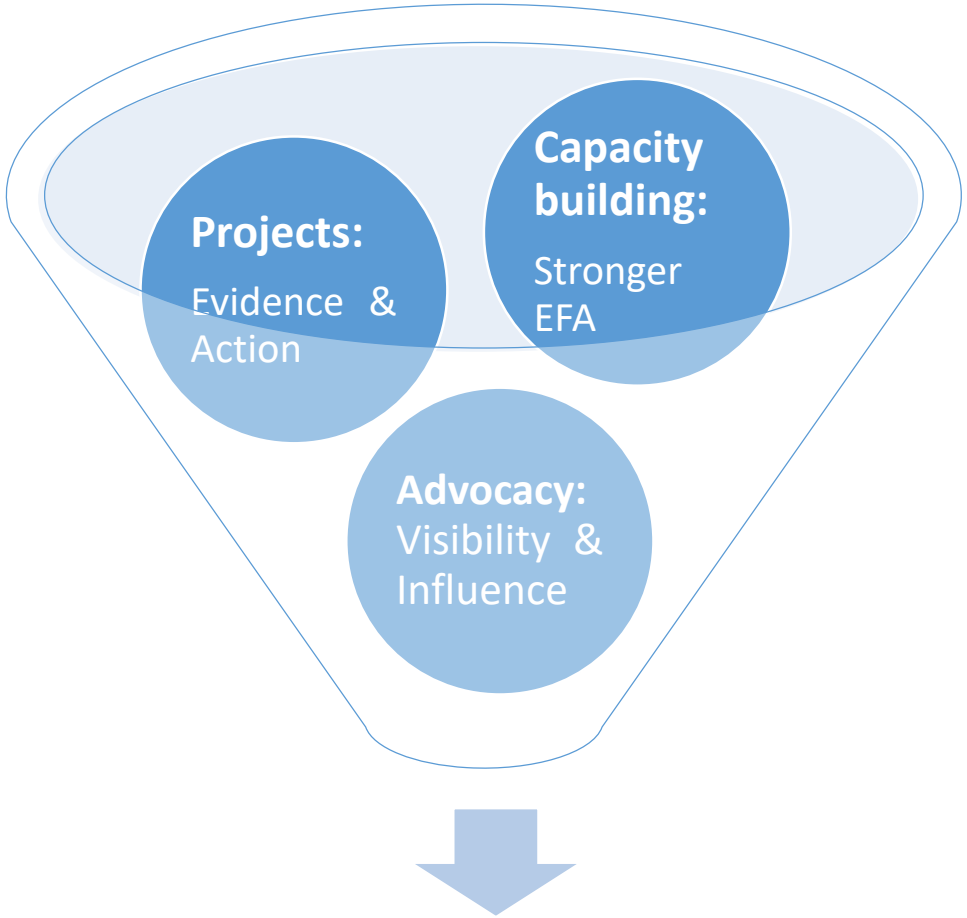
European Federation of Allergy and Airways Diseases Patients' Associations

Fields of activity



Healthier environment, Access to care, Patient participation, Equality

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Our values

EFA's core values

Advocates at EU level for the needs of people with allergies, asthma and COPD;
Values all members equally;
Implements best practices;
Creates patient-driven projects;
Cooperates with healthcare professionals, scientists, other NGOs.

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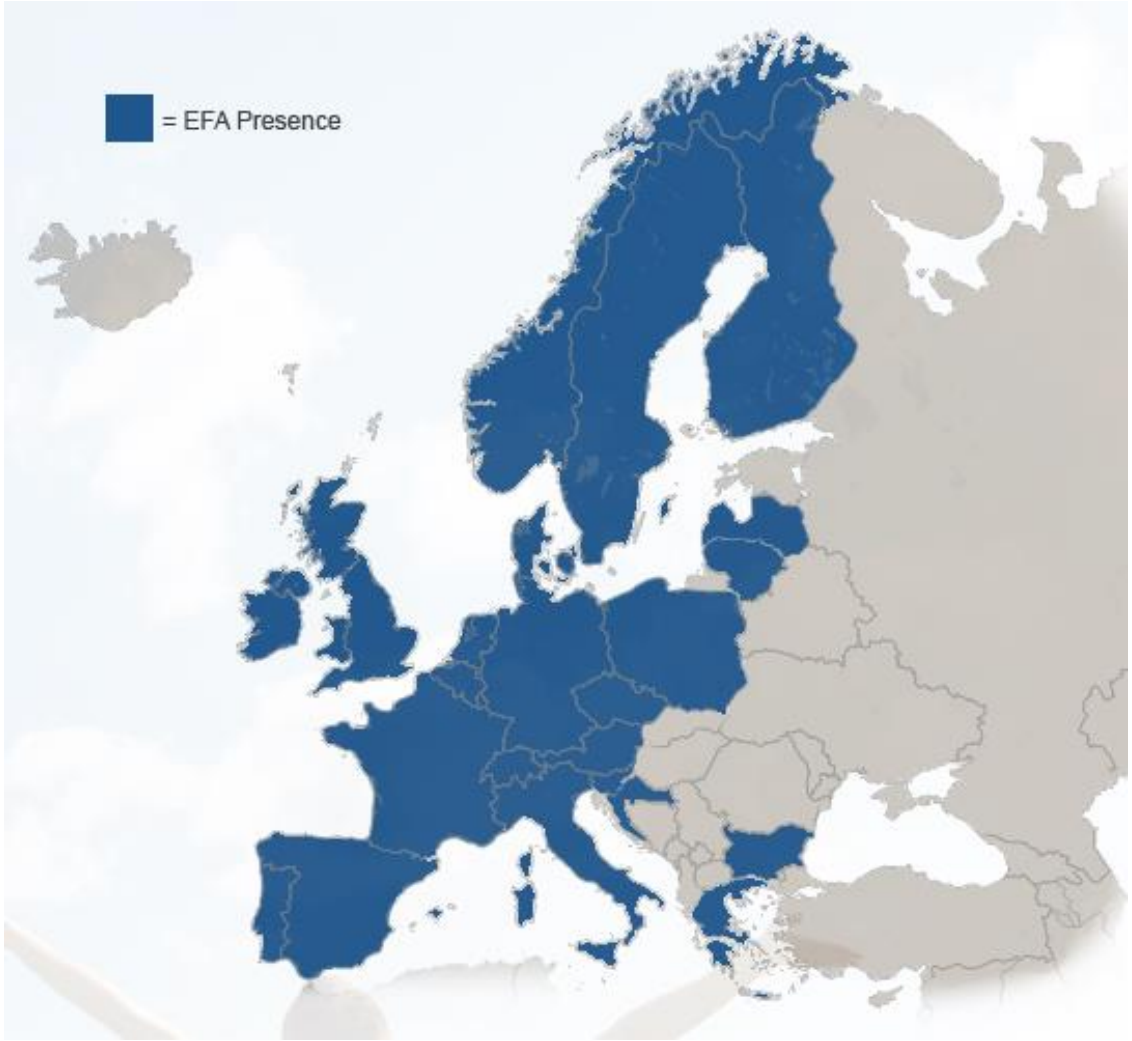
Membership



- Founded 1996
- 41 allergy, asthma and COPD patient organisations
- in 25 European countries
- Representing 500,000 patients in Europe

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Membership

EFA Family, AGM 2016, London

→Uniting patient groups at the EU level

→Sharing knowledge & best practices

→Capacity building

→Tools/Facilitation for policy change

→Collaboration (among members and with other EFA's partners, eg EPF, ERS)

myAirCoach project

- **mHealth personalised asthma monitoring system**
  - empowering and guiding patients with asthma to manage their own health
- **Real-time monitoring** of the clinical disease to allow
  - **direct feedback** to the patient at home or outdoor, without direct face-to-face contact in a healthcare setting
- A synergetic approach of ergonomic, compact and efficient
  - **sensor-based devices**, in communication with a **mobile device**

A "personal mHealth guidance system“ empowering patients to optimize their treatment – **FOR PATIENTS, WITH PATIENTS**

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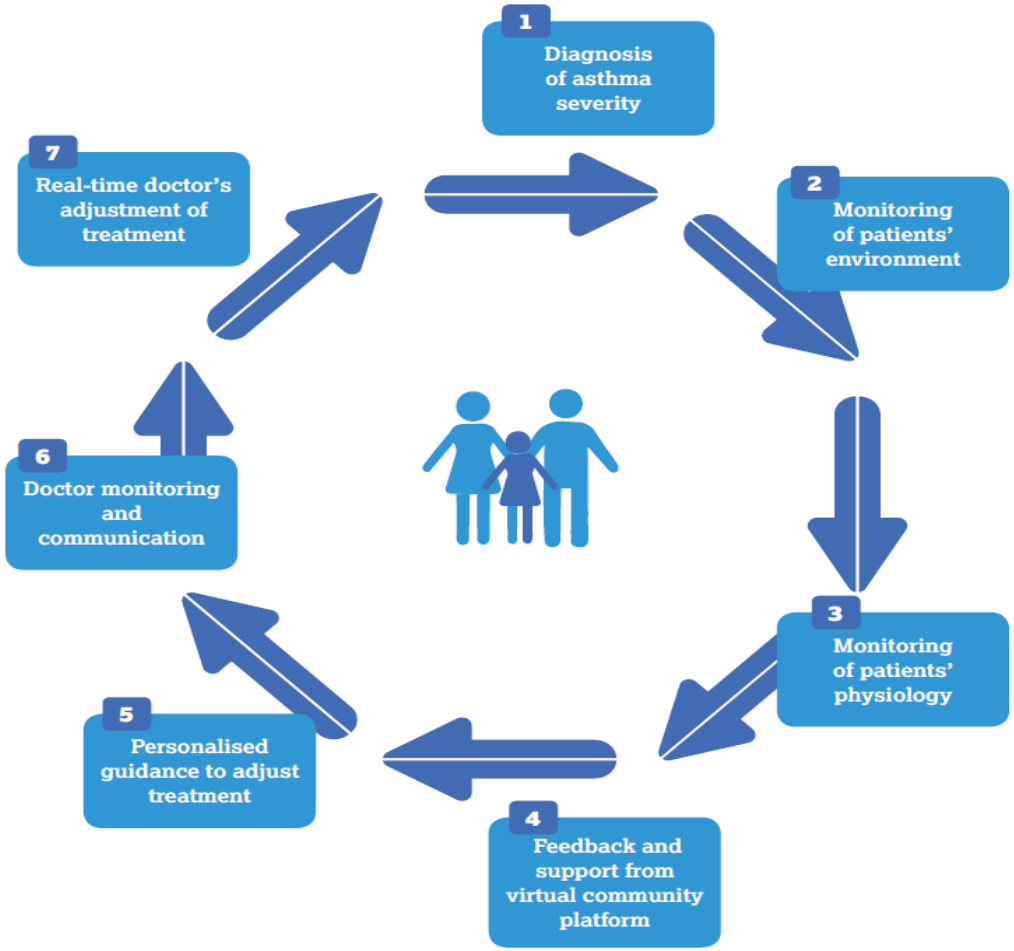
myAirCoach optimal treatment



myAirCoach User-centred design

Establishment of the **Advisory Patient Forum**:

- To provide **continuous feedback** from patient experts to other members of the consortium
- To assure **inclusion of the patients' perspective** across all project Work Packages
- To ensure the asthma management models will address the **specific needs of patients** and will be understandable for the lay target group.

22 adults with asthma from **4** countries

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Advisory Patient Forum activities

Definition of **User requirements**

- Review of the questions to be used in focus groups for patients and health professionals
- Review of the consent form, participant information sheets, letters of invitation for focus group and survey

Input on **Test Campaign**

- Review of the methodology
- Review of the consent form and participant information sheets for test campaign

Feedback on **usability** (online platform, virtual community) and educational content **(3D instructions** for proper use of MDI inhalers)

Lay summaries and presentation to events

- Presentation on "Patient involvement in designing mHealth systems for asthma self-management" at EASYM

Communication activities

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The perspective of the patients

How to develop a user-centred system?

A mixed methods research study:

focus groups ➡ development questionnaires ➡ dissemination patients/HCPs

(identification of potential uses)

What asthma patients would like from mHealth system and what HCPs believe is useful

- Patients request mHealth system to monitor asthma over time and to collect data to present to healthcare teams
- HCPs prefer functions alerting patients to deteriorating asthma control and advising when to seek medical attention
- 46% of patients and 79% HCPs find useful to have an asthma action plan incorporated into mHealth system ➡ reason behind not apparent
- HCPs would like the system to provide instructions on how to manage their asthma in an emergency (73% vs 22% of patients)
- HCPs are more in favor than patients (76% vs 36%) of a system that can tell if changes to patient's asthma medication has improved their asthma control

The perspective of the patients

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What are useful measurements for managing asthma?

- Measurements of lung function (peak flow, airway inflammation) and of breathing (breathing rate, cough) identified as helpful to maintain asthma control (71% and 64%)
- Measurements regarding environmental conditions were believed to be helpful for asthma self-management
- Measurements of medication adherence and inhaler technique should be integrated in the system according to most HCPs (vs only 45% of patients)

Acceptability and barriers

- Different requirements for different populations (children, elderly, severe asthma patients)
- The system may need to be personalised at an individual level
- Measuring numerous irrelevant parameters might discourage acceptance
- Limit the burden of inputting data ⇒ make the system as automated as possible
- Concerns with subjective measurements, such as self-reported symptoms
- Interpretation of data as source of possible error ⇒ authomated system vs individuals?
- 76% of patients are willing to carry or wear an additional device; 72% are willing to keep an additional device at home ⇒ but, this depends on the product design

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35 Rue du Congrès
1000 Brussels
Belgium

Website: www.efanet.org
Email: info@efanet.org
Twitter: @EFA_Patients