

Patient involvement in practice: lessons from the EU project U-BIOPRED

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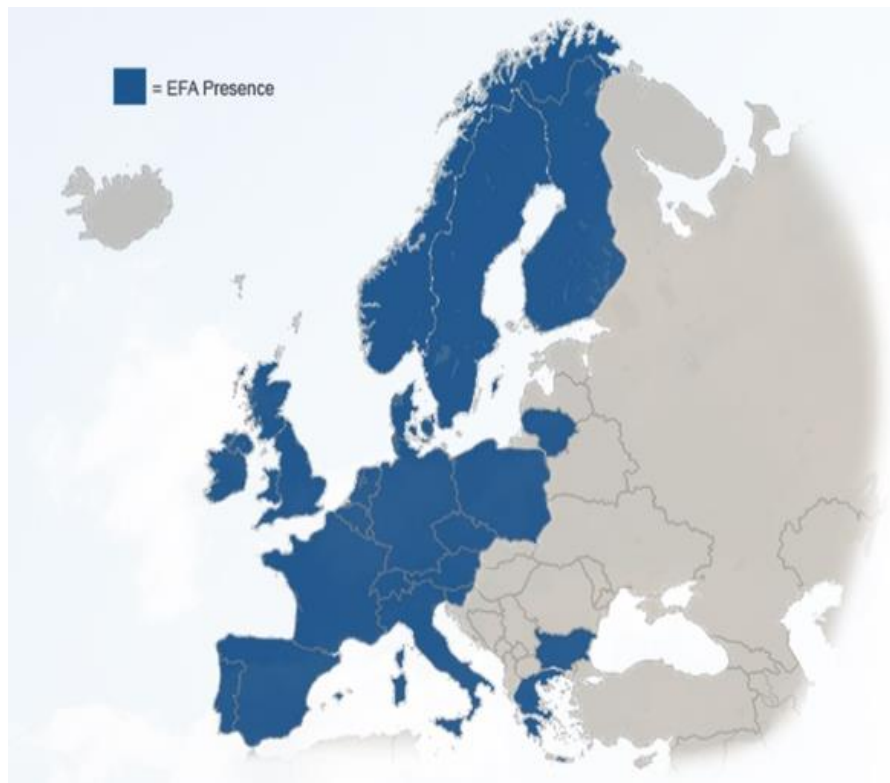
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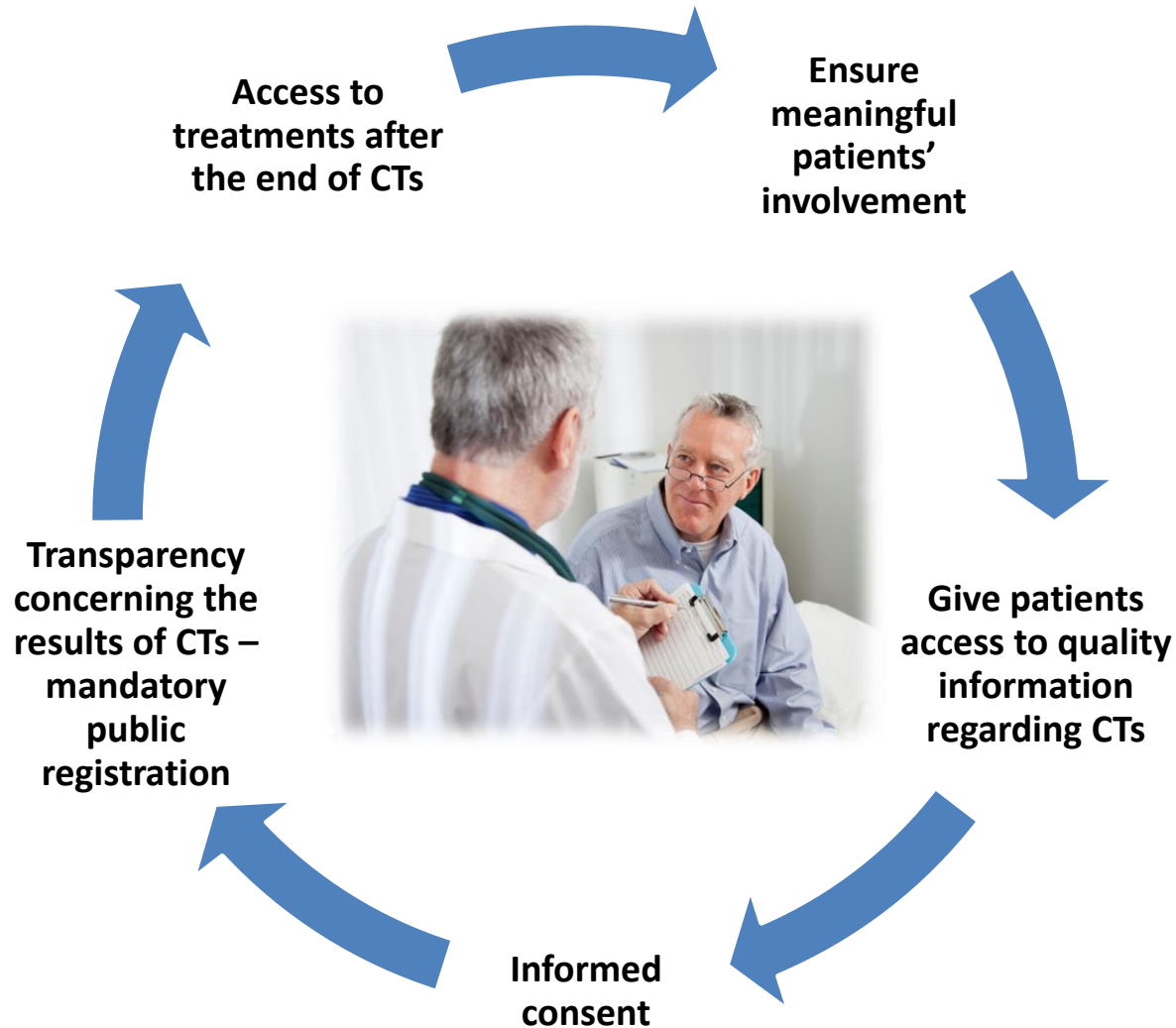
About EFA



- EFA has its Central Office in Brussels, Belgium

- The European Federation of Allergy and Airways Diseases Patients Associations (EFA) was founded in 1991
- EFA is a European network of 35 allergy, asthma and COPD patient organisations in 22 European countries
- EFA unites patient associations at the European level and seeks to improve the health and quality of life for patients and their families by facilitating collaboration and sharing knowledge and experiences

Five key issues for CTs



Subjects, patients, participants...?

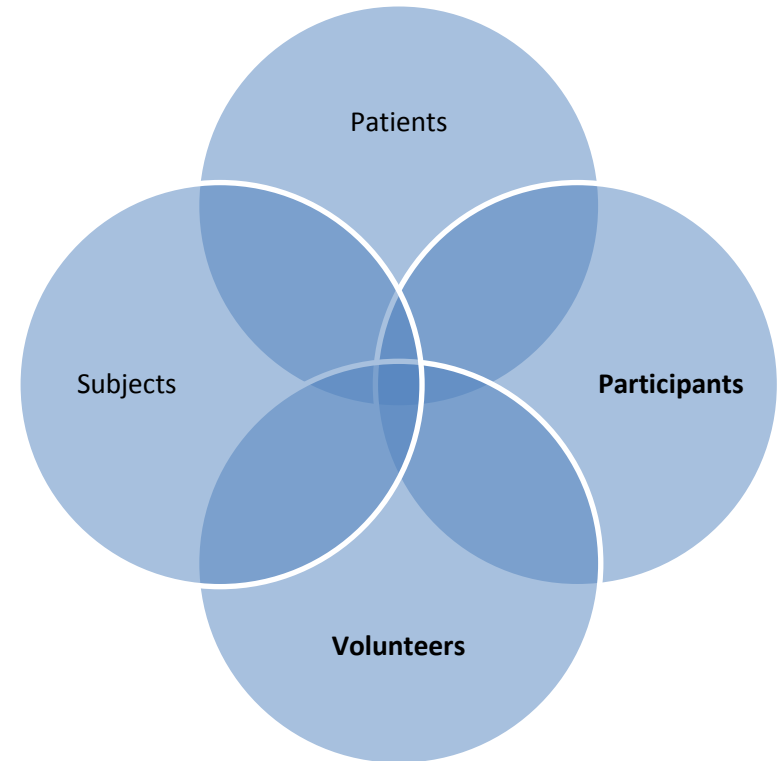
Subject → *something* rather
than an actual person

Patient → not everyone taking
part in a CT has to be a patient,
as there are also volunteers
without asthma

What is the **right word** then?

Others: *consumers, carers, lived experience, users*

ALL have potential pitfalls but preference is with **participants**



Why are patients important in U-BIOPRED?

“What would happen if patients were unwilling to participate? Nothing. That’s what would happen. **Trials would not be possible without willing participants.**

Under-recruitment was the project’s biggest risk. Who mitigated that risk? The study participants. By volunteering, 1025 study participants in U-BIOPRED themselves mitigated the project’s biggest risk.”

Scott Wagers, U-BIOPRED

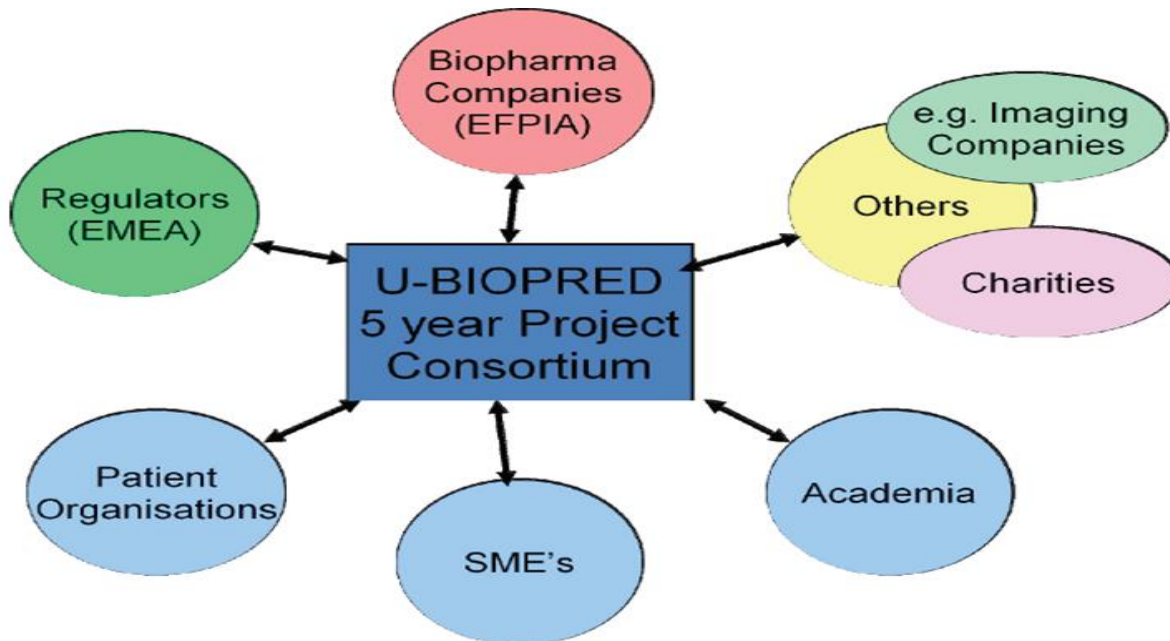


Unbiased Biomarker for the Prediction of Respiratory Disease Outcomes (U-BIOPRED)

Aim: to better understand the different types of severe asthma.

Starting Date: 01 October 2009 with duration of 60 months. This will enable us to:

- Better consider individual characteristics of patients (personalised medicine) in their diagnosis and management
- Make it easier to develop new and more effective medicines by overcoming the present bottlenecks to advancing new therapies.

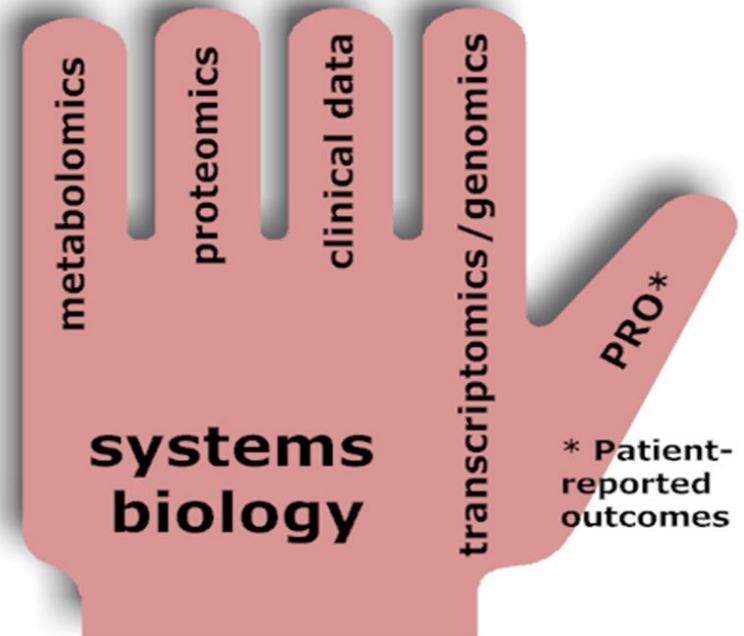


An integrated 'Systems Medicine' approach to understanding severe asthma

The resulting handprint will enable us to precisely characterise patients with different types of severe asthma = understanding different types of asthma better

- Studies like U-BIOPRED look to disrupt the notion that you can lump everyone with asthma together.
- The concept that there will be one cure for all of asthma is not yet relevant.
- *The desired outcome:* therapies that are focused more on the patient as an individual.

Each asthma patient is unique!



Uniqueness:
genetics,
environment and
lifestyle choices!

The role of participants in U-BIOPRED

- From the start patient organizations and patients themselves have been involved in U-BIOPRED.
- Not just as study participants, they helped in:
 - **designing the patient information sheets**
 - **the protocol**
 - **the overall focus**

Patients give the project meaning!

- U-BIOPRED's Patient Input Platform [PIP] provides feedback on a voluntary basis from patient's perspective on questions arising in different work packages or boards

Contributions of the Patient Input Platform [PIP]

- Patient representative and PIP member participation in the annual meetings for U-BIOPRED provided opportunities for interactions with researchers and each other



Lina Buzermaniene, Lithuania, patient representative in the Ethics Board
Per-Ake Wecksell, Sweden, patient representative in the Safety Board

- Contributions to meetings of the main clinical trial and viral challenge for weekly issues concerning experience of the study participants in trials
- The PIP helps shape dissemination and communication activities

The importance of empowering patients

Empowered patients:

- understand their health condition
- are able to participate in decision-making
- can make informed decisions
- take responsibility for their health and actively seek out, evaluate and use information

Empowering patients leads to:

- better healthcare outcomes
- less time for management of the disease
- less costs
- better quality of life

“What needs to happen is for doctors to come down off their pedestal and for patients to get up off their knees” - Robert Johnstone, IAPO



Thank you for your attention!

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Associations (EFA)

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