



# EUPATI Fellows experiences

# EUPATI Fellows



- EUPATI Fellows
  - Patient representatives who have completed the EUPATI Expert Patient Training Course
- EUPATI Patient Expert Training Course a key deliverable from EUPATI
- Needs assessment research led by Public Programmes has fed directly into the development of the course
- Two courses funded as part of the original EUPATI project grant undertaken by Public Programmes

# EUPATI Research



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Research

## BMJ Open What the public knows and wants to know about medicines research and development: a survey of the general public in six European countries

Suzanne Parsons,<sup>1</sup> Bella Starling,<sup>1</sup> Christine Mullan-Jensen,<sup>2</sup> Su-Gwan Tham,<sup>3</sup> Kay Warner,<sup>4</sup> Kim Wever,<sup>5</sup> on behalf of the Needs Assessment work package of the European Patients' Academy on Therapeutic Innovation (EUPATI) Project

To cite: Parsons S, Starling B, Mullan-Jensen C.

### ABSTRACT

**Objective:** To explore public knowledge of and

**Strengths and limitations of this study**

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Research

## BMJ Open What do pharmaceutical industry professionals in Europe believe about involving patients and the public in research and development of medicines? A qualitative interview study

Suzanne Parsons,<sup>1</sup> Bella Starling,<sup>1</sup> Christine Mullan-Jensen,<sup>2</sup> Su-Gwan Tham,<sup>3</sup> Kay Warner,<sup>4</sup> Kim Wever<sup>5</sup>

# Why develop training for patients in medicines R&D?



## Patients

- Seek up-to-date, credible, understandable information about medicines R&D
- Are largely unaware about clinical trials, translational research, personalized medicine, pharmacoeconomics, their key role
- Are interested in learning more particularly about what role they can play in medicines R&D

# Why develop training for patients in medicines R&D?



## ■ Patient advocates...

- Like to advise on protocol design, informed consent, ethical review, marketing authorization, value assessment, health policy
- Need further education and training to participate further as a partner in medicines R&D

# Areas covered by the European Patients' Academy



1. **Discovery of Medicines & Planning of Medicines Development**
2. **Non-Clinical Testing and Pharmaceutical Development**
3. **Exploratory and Confirmatory Clinical Development**
4. **Clinical Trials**
5. **Regulatory Affairs, Medicinal product Safety, Pharmacovigilance and Pharmaco-epidemiology**
6. **Health Technology Assessment and the economics**

**...and *NOT*:  
develop indication-  
or therapy-specific  
information!**

# To bring this to life, EUPATI develops education targeted at different levels



**EUPATI Patient Experts  
Training Course**  
-- for expert patients

**100**  
patient  
advocates

**English**



**EUPATI Educational  
Toolbox**  
-- for patient advocates

**12.000**  
patient  
advocates

**English  
French  
German  
Spanish  
Polish  
Italian  
Russian**



**EUPATI  
Internet Library**  
-- for the health-interested public

**100.000**

# EUPATI Patient Expert Training Course



## Outline

- 150+ hours of e-learning and two 4-day sessions
- Two cycles of 50 participants
- Open to patients, carers, patient advocates and volunteers

## Selection

- By the application deadline for the first 50 trainees, more than 300 applications were received! Great demand from the patient community!
- Selection was done by selection panel based on solid criteria
- Start of course:  
Oct 2014 (1<sup>st</sup> 53 trainees),  
Sept 2015 (2<sup>nd</sup> 50 trainees)



# EUPATI Fellows experiences of training and impact on future work



- Jill Praver
- Maria Piggin
  
- Talk a little about themselves and their advocacy work
- Decision to undertake the EUPATI training course
- Experience of EUPATI training, impact on advocacy work
- Plans for involvement in medicines R&D in the future