

EUPATI: The Informed Patient as Stakeholder in Drug Development

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on Therapeutic Innovation



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Unmet need of patient & public on info about medicines R&D

- **Patients...**

- seek up-to-date, credible, understandable information about innovation in treatments
- are largely unaware about clinical trials, translational research, personalized medicine, health economics, their key role in research

- **Patient advocates...**

- like to advise on protocol design, informed consent, ethical review, marketing authorization, value assessment, health policy
- lack the education and training required to participate as a partner in drug research and development

Patients can largely contribute to medicines R&D

- **Before research starts**
 - Identify indications, therapy gaps, patient population
 - Ethical/risk/benefit dilemmas
 - Patient-oriented outcome measures (PFS vs OS)
- **While research is in progress**
 - Managing expectations: hope/hype
 - Patient recruitment, retention
 - Quality of life, side effect monitoring
- **After conclusion of research**
 - Dissemination of research results
 - Improving adherence
 - Assessment of (cost-)effectiveness



More educated patient advocates needed to be empowered for R&D



& ICREL-Report 2009

~5.000
clinical trials
/ year

~9.400 trial applications
per year

In 1.250 multinat. Trials/year
alone: 5.000 ethics panels,
35.000 ethics reviewers



Millions of patients

100.000s of patient organisations

~200 pan-EU patient
organisations

~100 advocates
with R&D
expertise

The European Patients' Academy on Therapeutic Innovation

- ▶ Launched Feb 2012
- ▶ Runs for 5 years
- ▶ 29 consortium members
- ▶ Supported by IMI JU (EU-FP7 and EFPIA)



Paradigm shift in empowering patients on medicines R&D

IMI-funded EUPATI will

- ▶ **develop and disseminate** accessible, well-structured and user-friendly information and education on medicines R&D
- ▶ **build competencies and expert capacity about medicines R&D** among advocates, patients and the public
- ▶ **create the leading public library** on patient information in six most common languages under public licensing
- ▶ **facilitate patient involvement in R&D** to support industry, academia, authorities and ethics committees



Key topic areas



- 1. Medicines development process from research to approval**
- 2. Personalized and predictive medicine**
- 3. Drug safety and risk/benefit assessment of medicines**
- 4. Health economics and health technology assessment**
- 5. Design and objectives of clinical trials, including role of stakeholders**
- 6. Patients roles & responsibilities in innovative medicines development**



Audiences: advocacy leaders and the public at large



EUPATI Certificate Training Programme

Patient Ambassadors in committees, HTA agencies, industry, regulatory bodies, academia etc

Patient Journalists raising awareness

Patient Trainers for patient communities and networks.

100
patient
advocates



EUPATI Educational Toolbox

Educational tools for patient advocates (print, slide shows, eLearning, webinars, videos) for patient advocates

12.000
patient
advocates



EUPATI Internet Library

Patients & lay public at large, e.g. on specific aspects of the development process of medicines for patients with low (health) literacy.

100.000
individuals

Reflecting EU diversity: 7 languages



- **7 most frequently spoken languages:**
English, French, German, Spanish, Polish, Russian, Italian
- **Serving 12 European countries:**
UK, Ireland, Malta, France, Luxemburg, the francophone Belgium and Switzerland, Germany, Austria, the German-speaking Part of Switzerland, Spain, Italy and Poland, plus Russian-speaking population in CEE

Strong consortium & strong governance

- Leading pan-EU patient umbrella groups
- Strong impetus from key academic partners and research organisations
- Industry expertise in medicines R&D
- Advisory bodies & codes committed to ensure independence and good governance
 - EMA, Swissmedic, MHRA, BfArM
 - Key experts in bioethics, genetics, HTA, economics, evidence based med, patient advocacy



What we will have achieved by 2016



- EUPATI platform fully loaded with training, education, information material in multiple languages
- EUPATI Patient Ambassador, Patient Journalist, Train-the-Trainer Programme in place
- Good practice guideline for patient involvement released
- Annual Conferences and at least 5 Regional Workshops performed. Expert network established.

First public EUPATI Meeting: today!

- Hotel Bella Sky Comwell, Copenhagen very close to this conference, 27 March, 14:00-15:30
- Please join us today!



More Information on patientsacademy.eu



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