EUPATI: The Informed Patient as Stakeholder in Drug Development

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24th Annual EuroMeeting
26-28 March 2012
Copenhagen, Denmark
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

- ~5,000 clinical trials / year
- ~9,400 trial applications per year
- In 1,250 multinational 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

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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.

**EUPATI Educational Toolbox**
Educational tools for patient advocates (print, slide shows, eLearning, webinars, videos) for 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 patient advocates
12,000 patient advocates
100,000 individuals

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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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