



Innovative Medicines Initiative

The European Patients' Academy on Therapeutic Innovation

Nicola Bedlington, EPF



efpia*

PREMISE



- **Patients across the EU** want and need more information on therapeutic innovation -but are unaware of research & their role.
- **Patient advocates** play a key role in providing information, but **may lack education and training to participate** in research and drug development processes



EUPATI Setting the Scene

- A project of the Innovative Medicines Initiative (IMI)
- Third Call –Topic 9
- Consortium of 29 partners
- Start Feb 2012



europeanpatients'forum



vfa.

AMGEN

AstraZeneca



Boehringer Ingelheim



IPPOSI
Irish Platform for Patients' Organisations,
Science and Industry

Chiesi

ESTEVE

farmaindustria

gsk

janssen
PHARMACEUTICAL COMPANIES
of Johnson & Johnson

nowgen
A Centre for Devices in Healthcare



BIO PEOPLE



Lilly

MERCK

NOVARTIS

novo nordisk

Roche



sanofi
etipia



EUPATI: European Patients' Academy on Therapeutic Innovation



- ▶ **develop and disseminate** accessible, well-structured and user-friendly information and education resources on therapeutic innovation
- ▶ **build competencies** among well informed patients and the public about pharmaceutical R&D
- ▶ **build expert capacity** in patient advocates
- ▶ **create the leading public library** on patient information in six most common languages
- ▶ **establish a widely used, sustainable infrastructure** for objective, credible, correct and up-to-date knowledge
- ▶ **facilitate patient involvement in R&D** to support industry, academia, authorities and ethics committees



What we aim to achieve



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

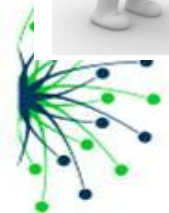
12.000
patient
advocates



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



Maximum outreach in Europe



- ▶ **6 most frequently spoken languages:**
English, French, German, Spanish, Polish, and Russian
- ▶ **Serving 11 European countries:**
UK, Ireland, Malta, France, Luxemburg, the francophone Belgium and Switzerland, Germany, Austria, the German-speaking Part of Switzerland, Spain, and Poland, plus Russian to reach a large Russian-speaking population in CEE countries.
- ▶ In case additional budget becomes available, selected materials will be translated into **RO, IT, PT, HU, GR.**
- ▶ **Industry translation resources, translation schools and patient volunteers** will be engaged for the translation of EUPATI materials



Topics addressed by EUPATI



Implementation by WP4 task forces

Needs Assessment

Content Sourcing

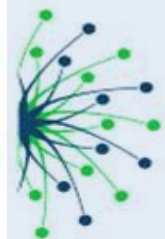
Content Development

Quality Control

Quality Assurance/
Validation (WP6)

Delivery /
Deployment (WP6)

- ▶ **TF1: Medicines development process from research to approval**
- ▶ **TF2: Personalized and predictive medicine.**
- ▶ **TF 3: Drug safety and risk/benefit assessment of medicines**
- ▶ **TF 4: Pharmacoeconomics and health technology assessment.**
- ▶ **TF5: Design and objectives of clinical trials (& involved stakeholders)**
- ▶ **TF 6: Patients roles & responsibilities in innovative medicines development**



efpia

Independence



- ▶ **Quality control** (WP 4 content)
- ▶ **Quality assurance** (WP6 implementation)
- ▶ **Regulatory Advisory Panel** involving 4 regulatory bodies EMA, BfArM, Swissmedic, MHRA.
- ▶ **Project Advisory Board** with leading independent experts from different areas, including Cochrane
- ▶ **Ethics Framework and ethics panel**
- ▶ **EUPATI Code of Practice -**





Thank you!

Nicola Bedlington - nicola.bedlington@eu-patient.eu