An update on the state of play for EPF members EPF AGM 13 May 2014

Jytte Lyngvig, Director DIA EMEA and Nicola Bedlington

The project is receiving support from the Innovative Medicines Initiative Joint Undertaking under grant agreement n° 115334, resources of which are composed of financial contribution from the European Union's Seventh Framework Programme (FP7/2007-2013) and EFPIA companies.

Health research & policy is changing at a fast pace

Innovation transforms the lives of patients with serious, lifelong conditions:

- Molecular targets/pathways
- Genome sequencing
- Translational research
- Personalized medicine,
  Small trial populations,
  Biomarkers, Companion Diagnostics
- Need for post-marketing data
- Health Technology Assessment,
  QoL, endpoints, comparators
- BUT long term pressure on health budgets are probably here to stay

Patients have a key role in all aspects of health-related research

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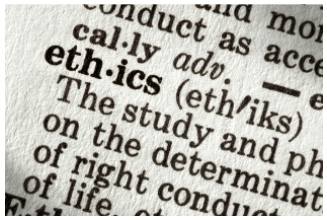
EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH
BfArM
MHRA
swissmedic

Competent authorities

Policy makers /Research Policy

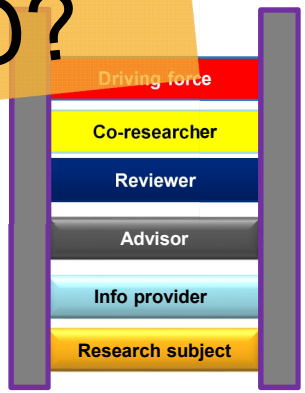
Trial protocol design
informed consent
review
marketing authorization
assessment
Public

Are there enough patient advocates to engage in R&D?



Research Ethics Committees

HTA agencies & committees



Clinical Research

European Patients' Academy: Paradigm shift in empowering patients on medicines R&D

- Launched Feb '12, runs for 5 years,
  30 consortium members,
  Funded by Innovative Medicines Initiative

- will **develop and disseminate objective, trustworthy, public knowledge about medicines R&D**

- will **generate knowledge and facilitate patient involvement in R&D** to collaborate in academic & industry research, authorities and ethics committees

- Will address informational needs and help reduce myths and misconceptions.

Project coordiated by EPF, led by 4 key pan-European patient associations, strong consortium

EUPATI
European Patients' Academy on Therapeutic Innovation

EPF European Patients Forum

EURORDIS
Rare Diseases Europe

EGAN
Patients Network for Medical Research and Health

EATG
EUROPEAN AIDS TREATMENT GROUP

Content production of objective, reviewing material is currently in full swing

1. **Discovery of Medicines & Planning of Medicine Development**
2. **Pre-Clinical Testing and Pharmaceutical Development**
3. **Exploratory and Confirmatory Clinical Development**
4. **Clinical Trials**
5. **Regulatory Affairs, Medicinal Product Safety, Pharmacovigilance and Pharmacoepidemiology**
6. **HTA principles and practices**

+ Patients' roles and responsibilities

…but NOT:
indication- or therapy-specific information!

We develop education material targeted at different levels

EUPATI Certificate Training Programme
for expert patients

100
patient advocates

EUPATI Educational Toolbox
for patient advocates

12,000
patient advocates

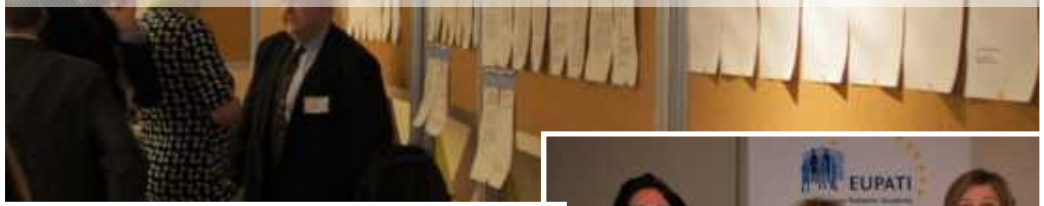
EUPATI Internet Library
for the health-interested public

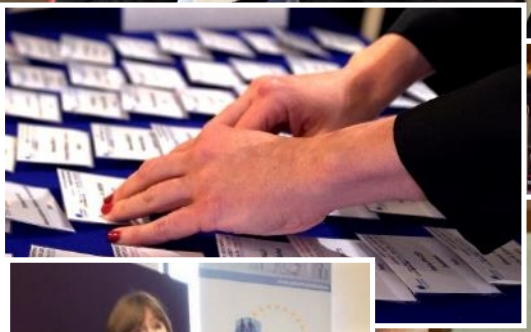
100,000
individuals

English
French
German
Spanish
Polish
Italian
Russian

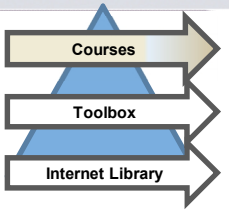
Two years of EUPATI: Much has been done! …

For example in Frankfurt 2012, Barcelona 2013, Rome 2013, Warsaw 2014…





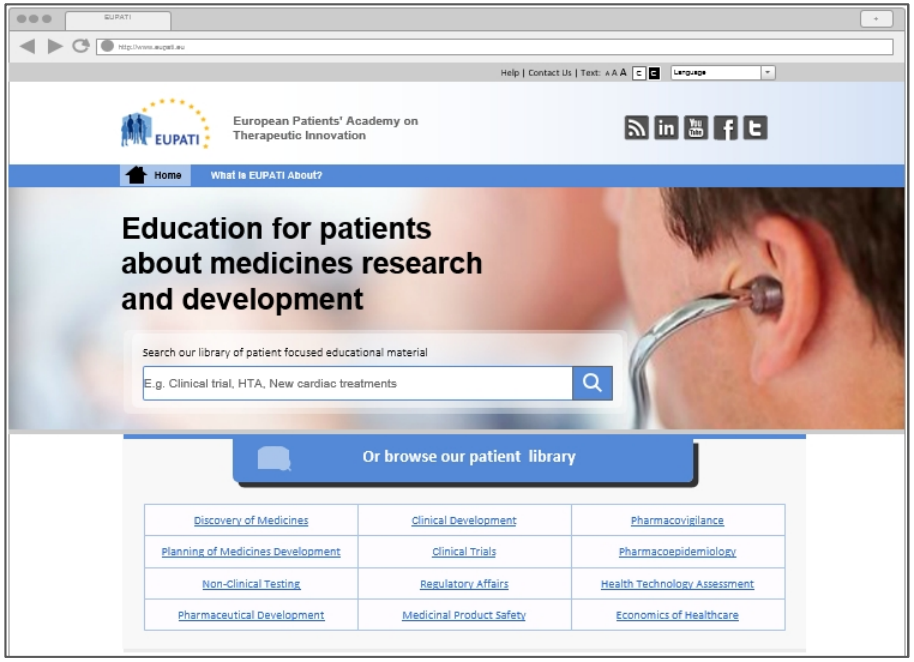
EUPATI Certificate Training Course

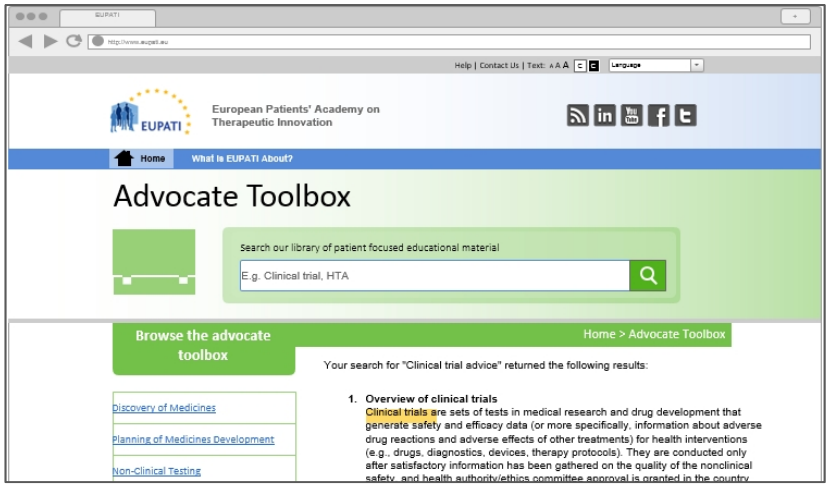


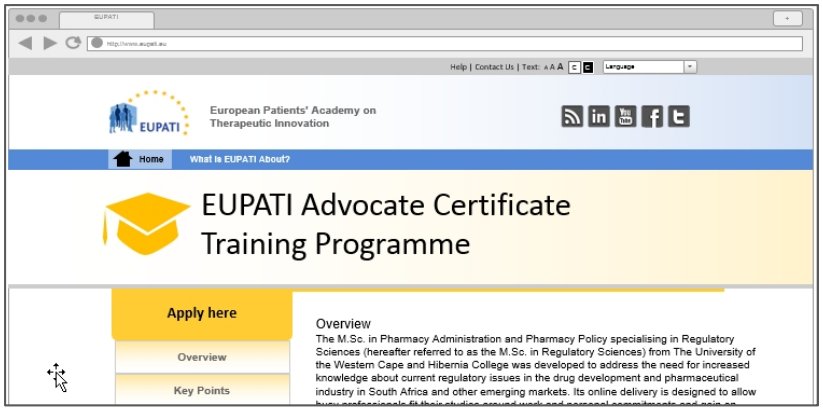
- 150+ hours of e-learning and two 4-day sessions
- Two cycles of 50 participants
- Open to patients, carers, patient advocates and volunteers

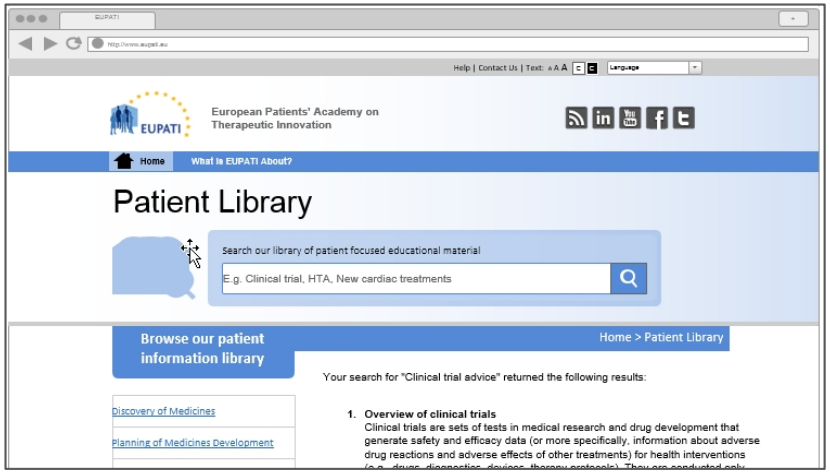
- **By the application deadline for the first 50 trainees, more than 300 applications were received!** Great demand from the patient community!
- Start of course:
  Sept 2014 (1st 50 trainees),
  Sept 2015 (2nd 50 trainees)

The (future) EUPATI web platform and content is taking shape



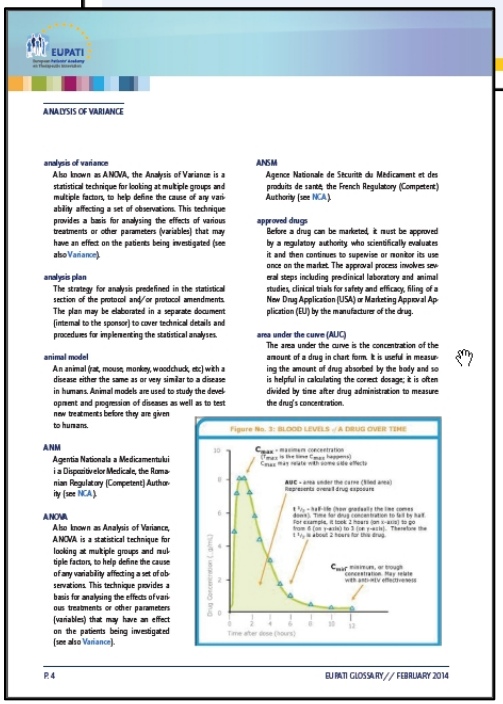






EUPATI's first R&D Glossary... (Your input is appreciated!)

- EUPATI's first glossary of terms and definitions of medicines R&D.
- ~460 terms drawn from course content
- This is a **first draft**.
  → Feedback form & return address on last page
- A more lay friendly version is being developed for public use, plus an interactive version within online training course.



EUPATI National Platforms: Partnership on the country level

EUPATI National Platforms will...

- **make sure EUPATI understands educational needs** in R&D on national level when developing content
- **disseminate EUPATI's existing training material and information** on the national level
- **To raise public interest about EUPATI** in 12 countries
- **To identify training faculty, logistics and financial support** on the national level

AT
BE
CH
DE
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FR
IT
IE
LUX
MT
PL
UK

EUPATI in 2016:
What we will have achieved

- EUPATI platform fully loaded with training, education, information material in multiple languages
- 100 patient advocates trained in-depth and received the ‘EUPATI Certificate’
- 12 EUPATI National Platforms set up (with your help!)
- Good practice guideline for patient involvement released
- Annual Conferences and Regional Workshops performed. Expert network established.
- Sustainability strategy and long-term implementation of an “European Patients’ Academy” beyond 2017 completed

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European Patients Academy on Therapeutic Innovation

Be in touch!

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