EU patient-led training for patients:

European Patients' Academy: Overview & Status Quo

EMA, 26 Nov 2015

Jan Geissler, EUPATI Director

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.

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

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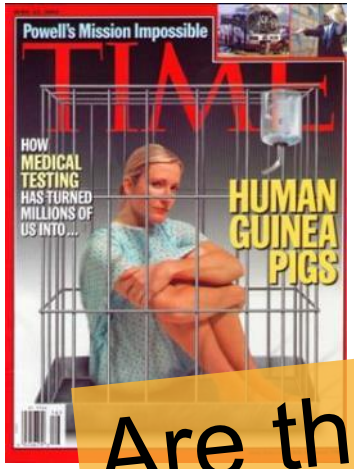


Public

EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH
BfArM
MHRA
swissmedic

Competent authorities

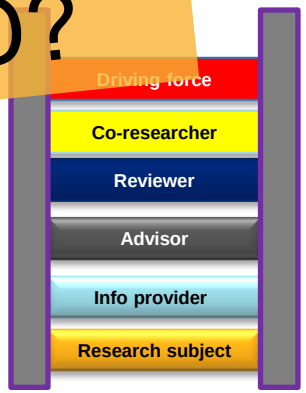
Policy makers /Research Policy

Trial protocol design, informed consent, clinical review, marketing authorization, value assessment, health policy

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

Research Ethics Committees

HTA agencies & committees



Clinical Research

What is EUPATI?

- **A Public Private Partnership** within the Innovative Medicines Initiative Joint Undertaking*
- **A 5-year project**, launched in February 2012
- **A patient-led project** coordinated by the European Patients' Forum, with EGAN, EURORDIS and EATG in key roles
- **A strong multi-stakeholder consortium** of patients' organisations, academia, NGOs and industry – 33 organisations
- **The key pan-European initiative** to build competencies & expert capacity among patients and the health-interested public

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* Resources are composed of financial contribution from the European Union's Seventh Framework Programme and in-kind and financial contributions from EFPIA companies

The EUPATI objectives are directly contributing to this paradigm shift

Key objectives:

1. **Develop and disseminate objective, credible, correct and up-to-date public knowledge about medicines R&D**
2. **Build competencies & expert capacity** among patients & public
3. **Facilitate patient involvement in R&D** to collaborate in academic research, industry research, authorities and ethics committees

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

Truly patient-led: 4 major pan-European patient associations in key roles

- EUPATI Project Coordination
- >50 umbrella patient organisations.

- Linking national and regional patient alliances

- >600 rare disease organisations in >45 countries

- >100 members in over 30 countries

Additional partners in other patient organisations and "members of members" via "EUPATI Network"

Strong consortium & strong governance

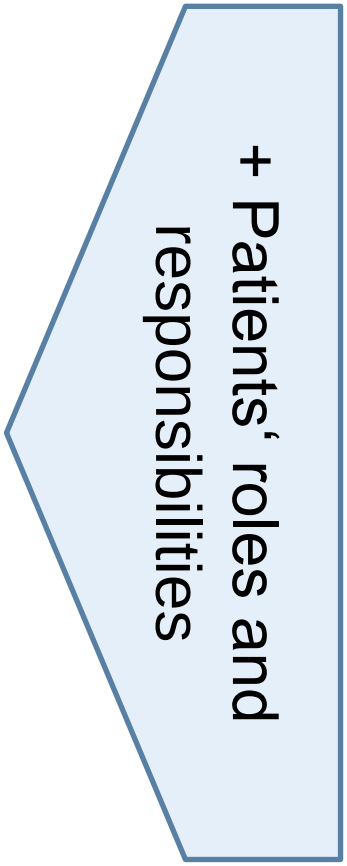
- Coordinated by patients (EPF)
- Leading pan-EU patient umbrella groups involved in all key activities
- Strong impetus from key academic partners and research organisations
- Industry expertise in medicines R&D

- Advisory bodies & codes committed to ensure independence and good governance
  - EMA, Swissmedic, MHRA, BfArM, AIFA
  - Key experts in bioethics, genetics, HTA, economics, evidence based med, patient advocacy

EUPATI empowers patients with education in key areas of medicines R&D

Educate and train patients and patient advocates with objective, credible, correct and up-to-date information about:

1. Discovery of Medicines & Planning of Medicine 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. HTA principles and practices



EUPATI is developing education targeted at different levels

EUPATI Patient Experts Training Course
-- for expert patients

100 patient experts

First course completed

EUPATI Educational Toolbox
-- for patient advocates

12.000 patient advocates

Launch 27 Jan 2016

EUPATI Internet Library
-- for the health-interested public

100.000 individuals

English
French
German
Spanish
Polish
Italian
Russian

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- Content can be copied, distributed, edited, remixed, and built upon, on a non-commercial basis
- Authorship and licensing needs to stay intact and mentioned on all derivatives
- Similarly applied by e.g. Wikipedia, Google, many others

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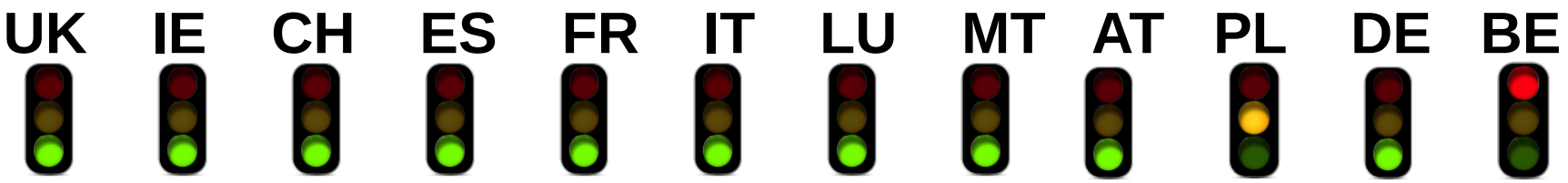
Engage in EUPATI National Platforms

EUPATI National Platforms...

- **bring all stakeholders together in countries**
- **address educational needs** in R&D
- **disseminate EUPATI's training material to patient organisations**



Patient Expert Training Course

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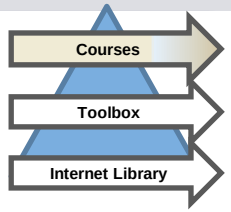
Online self-learning **2 Face-to-face events** **Patient involvement forum**

150-175 hours of e-learning

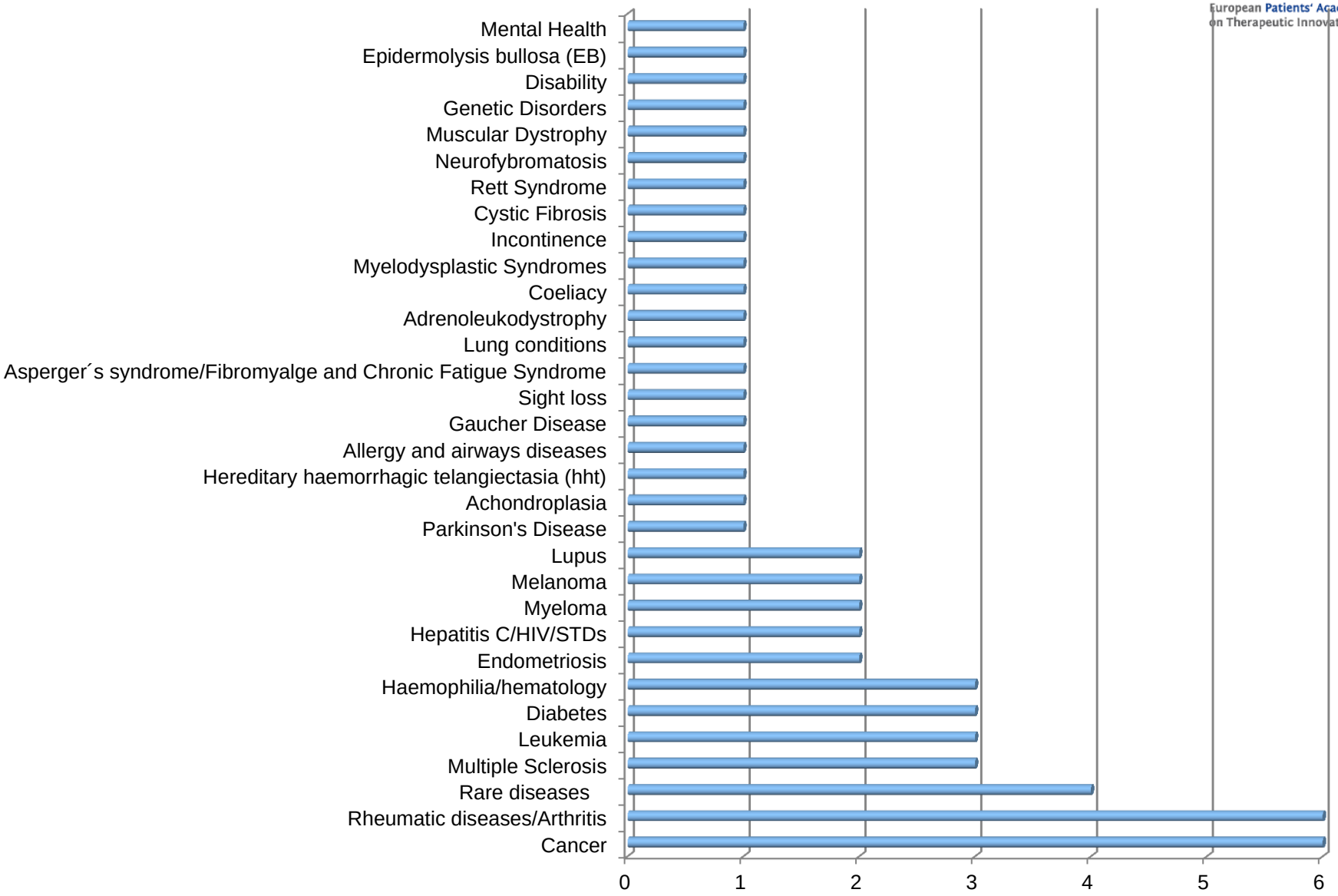
and 8 days for two Face-to-Face meetings over a period of 14 months

1st EUPATI's Patient Experts Training Course kicked off on 6 Oct 2014



- >200 Applications for 2 courses with ~50 trainees each
- Patient advocates from 30 countries and 28 disease areas enrolled
- 1st course graduating in Dec 2015

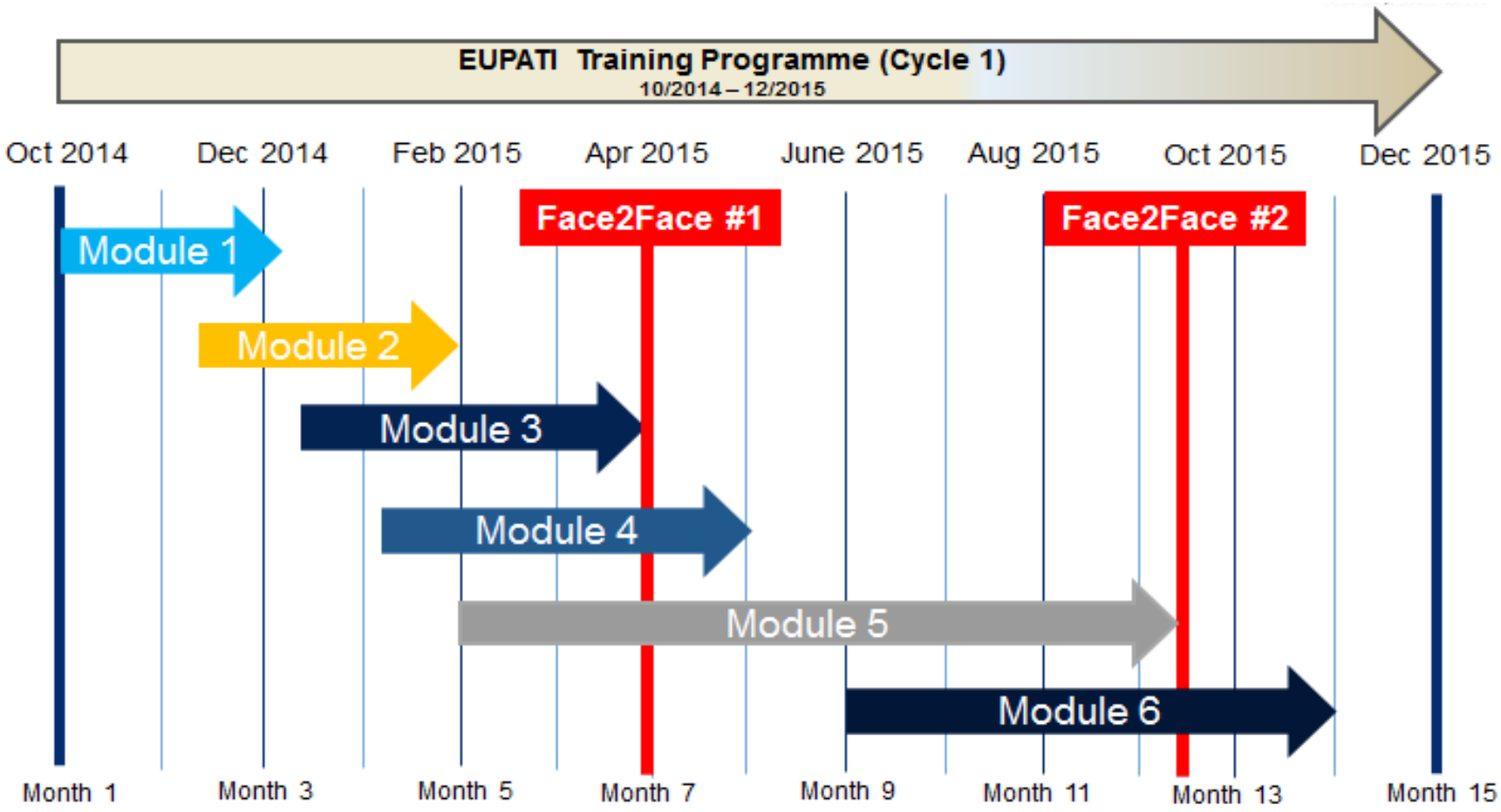
Course #2 trainees by disease area



EUPATI Patient Expert Training Course: Rollout of course modules

CONTENT DEVELOPMENT

DEPLOYMENT & DISSEMINATION



What our EUPATI trainees say about the EUPATI Patient Expert Training Course…

Margaret Graham McDonald from Scotland

(Healthcare Improvement Scotland):

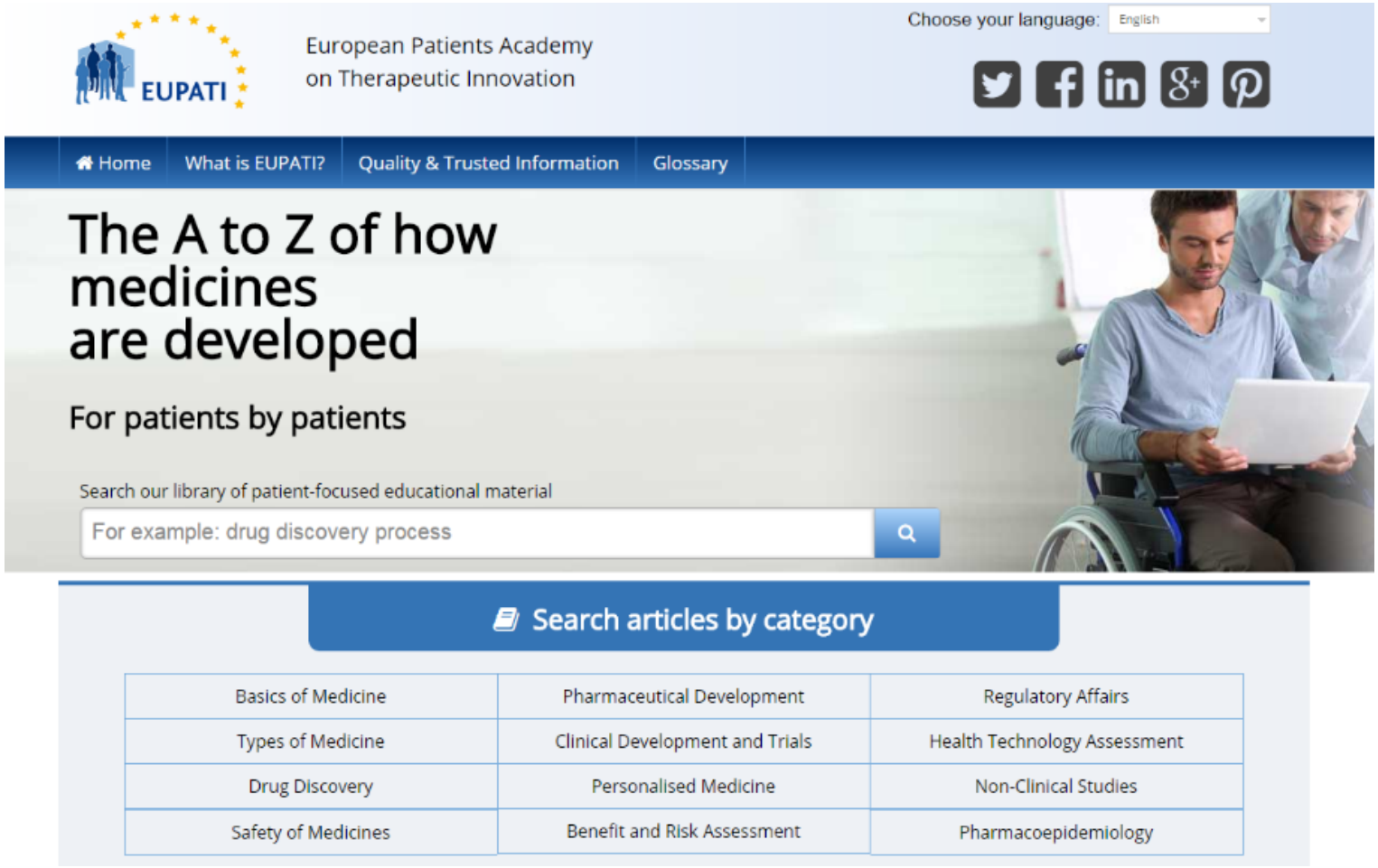
"The EUPATI course has harnessed the skills I needed to play an effective and active part in Research & Development with confidence."

Begonya Nafría from Spain

(Hospital Sant Joan de Déu, Barcelona):

"It´s essential that patients and their families are involved in research on rare diseases. They have an immense expertise, and their needs must be taken into account".

The EUPATI Advocate Toolbox in 7 languages (launch 27 January 2016)

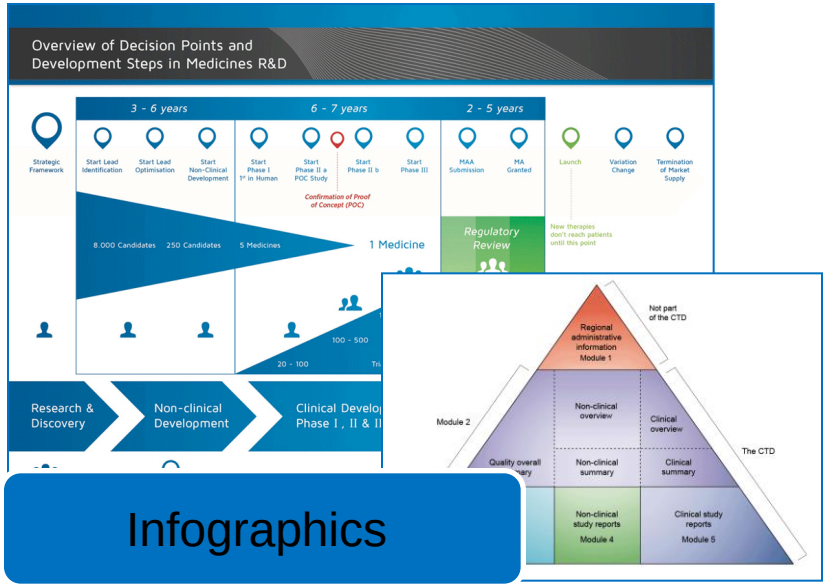


All content available in English, French, Italian, Spanish, German, Polish, Russian.

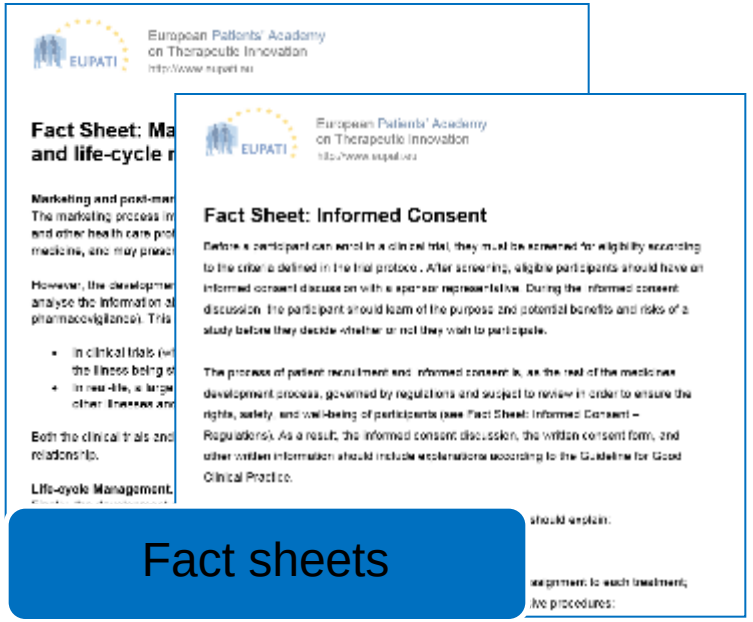
The Patients' Academy: Patient Advocate Toolbox – Formats

Articles

PowerPoints



Infographics



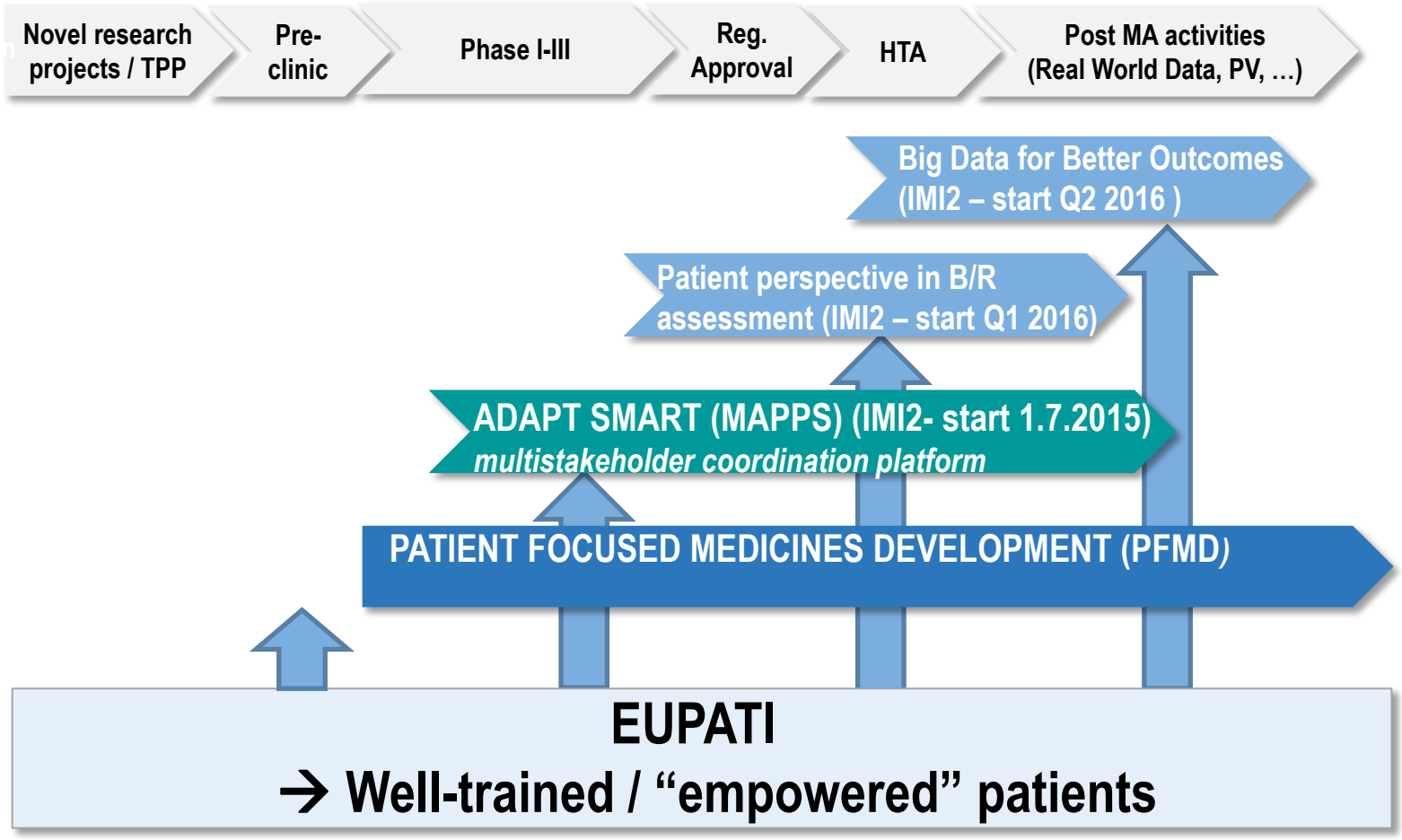
Fact sheets

Beyond EUPATI: Creating sustainable impact beyond 2016

By 2016, this unique EUPATI public private partnership has pioneered a paradigm shift towards patient involvement in medicines R&D:

- Developed and deployed Patient Expert Training Course
- Trained ~100 Patient Experts
- Deployed “EUPATI Toolbox” and “EUPATI Internet Library” in 7 languages
- Released EUPATI material under “Creative Commons License”
- Established ~12 EUPATI National Platforms
- Developed guidance on patient involvement in R&D with different stakeholders groups and established best practice procedures
- Established EUPATI as “quality brand” for patient education in R&D

EUPATI-trained advocates are the “baseline resource” for many R&D-related patient involvement initiatives



EUPATI
European Patients Academy on Therapeutic Innovation

can really make a unique difference to patient empowerment and to medicines R&D.

You can help us to make it a success.

Jan Geissler
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Multi-stakeholder development and review of the EUPATI materials

Internal production and review process

- Created by **experts from different stakeholders**
- **EUPATI Editorial Group** (comprising Patient Organisations, Academia, Industry, NGOs) collectively reviewed each topic to ensure content is consistent, avoids unnecessary duplication and is fit for intended audience/purpose.

External testing and review process

- **user-tested** with target audience
- reviewed by **independent Project Advisory Board members and Ethics Committee members**
- Relevant topics reviewed by **independent regulatory experts and HTA experts**
- **edited for appropriate language** by health literacy experts