Why EUPATI?

What is EUPATI?

EUPATI in Malta

Health research & policy is changing at a fast pace

EUPATI
European Patients' Academy on Therapeutic Innovation

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 – here to stay

Patients as partners: partnership model requires a paradigm shift, and more training for patients and advocates

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Patient roles in Medicines R&D (academia + industry)

Source: PatientPartner FP7 Project (2010)

Competent Authorities

Policy Makers/Research Policy

HTA Agencies/Committees

Research Ethics Committees

What is EUPATI?

- **A Public Private Partnership** within
- the Innovative Medicines Initiative
- Joint Undertaking*
- **A 5-year project**, launched in February 2012 but which is now continuing on as an EPF training programme since March 2017
- **A patient-led project** coordinated by the European Patients' Forum, with other *stake holders*
- **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

* 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

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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!

Last 24 months in facts and numbers

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216

– countries use the Toolbox

3,307

– users on busiest day in April 2018

EUPATI trainees graduated from Cohorts 1, 2, 3 – **152**

52,776

– European users of most used language

432,089 (613) **–words in the Toolbox (number of content pieces)**

13

- **6 ENP run webinars**
- **7 general webinars**

8 **– new sessions developed for Cohort 3 Event 1**

1,200,000 **– total users since launch**

Engage in
19+ 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**

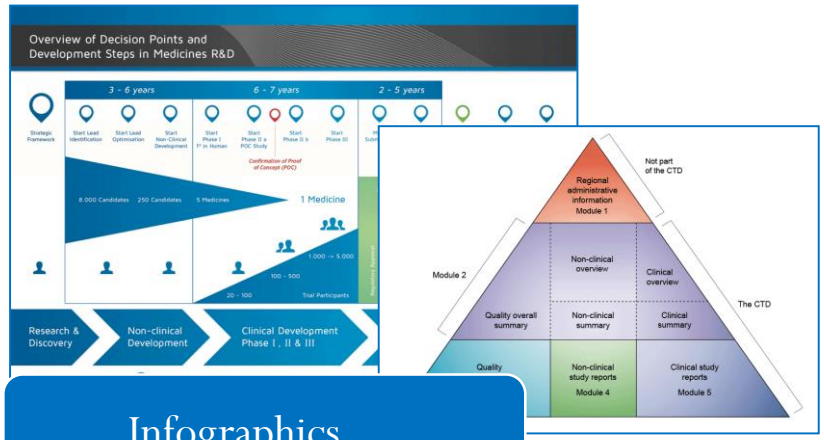
National platforms set up in AT, FR, DE, IE, IT, LU, MT, PL, ES, CH, UK, DK, SK, PT

Additional platform initiatives ongoing in NO, GR, RU, SRB, BE

EUPATI Toolbox on Medicines R&D: >3.500 content items

Articles

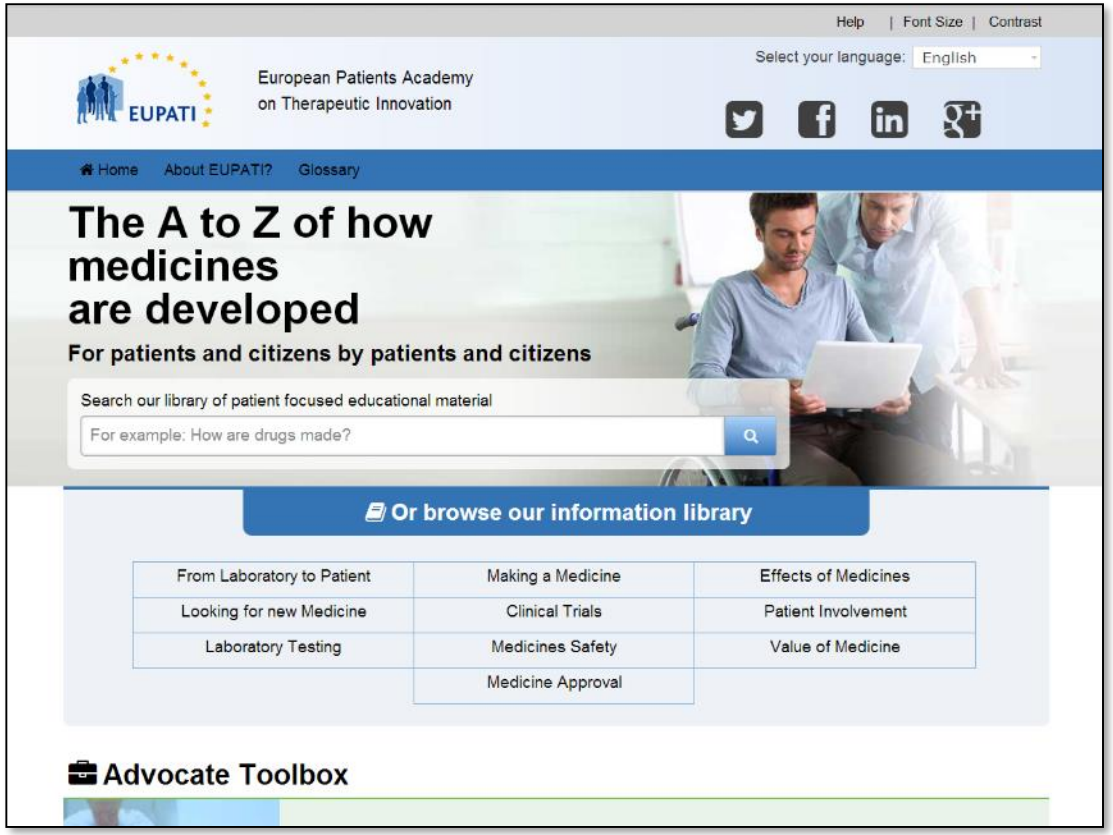
PowerPoints



Infographics

Fact sheets

EUPATI Toolbox on Medicines R&D in 10 languages including Maltese



- Fact sheets, detailed papers, PPTs, videos, illustrations, glossary.
- In Danish, English, French, German Italian, Maltese , Netherlandish ,Polish, Russian & Spanish.

Patient Expert Training Course

+

+

Online self-learning

2 Face-to-face events

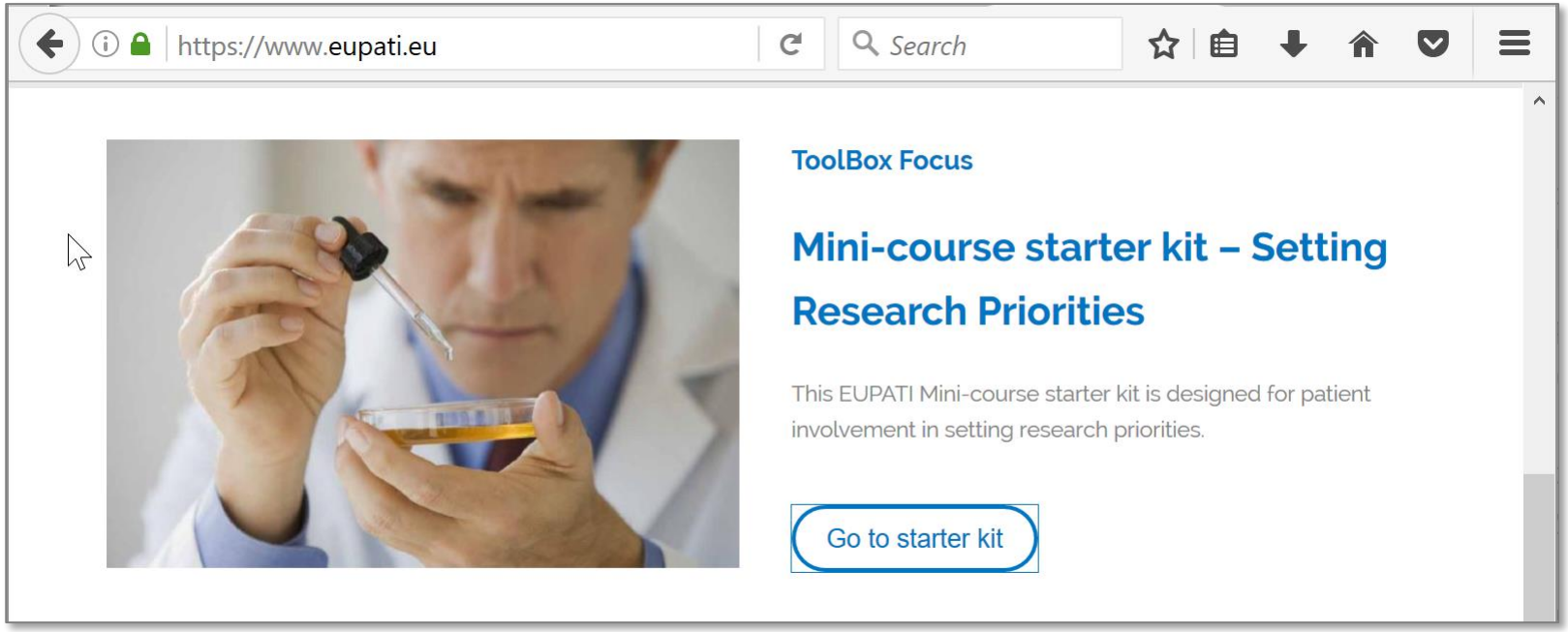
Patient involvement forum

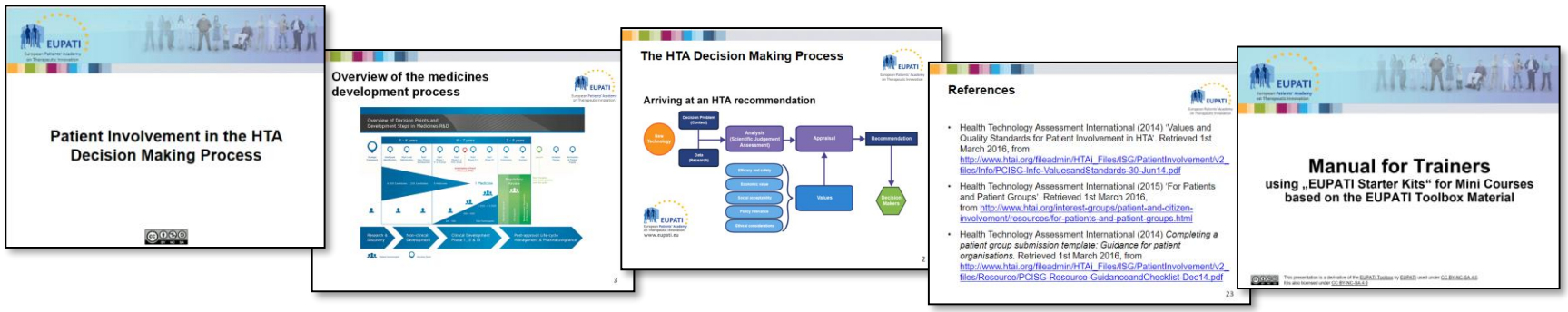
150-175 hours of e-learning

and 8 days for two Face-to-Face meetings

over a period of 14 months

EUPATI Mini-Course Starter Kits to run training days





EUPATI IN MALTA

EUPATI was launched in Malta in 2014.

I became a EUPATI expert after my Graduation, in December 2016. I became part of EUPATI National Platform (ENP). This allowed me to delivered presentations to different Patients Groups, Professionals Organisations, Lectures to University Students to raise awareness about Eupati and that people can access the module for more information.

- With the medical professionals, we encouraged them to promote the EUPATI site since it is a reliable and an easy site to follow for information on medicines since people like to surf the internet for medical information.

Positive aspects

- MHN kept project alive in Malta despite of various difficulties
- 2 patient experts trained and 3rd person accepted hopefully to start training later this year as patient expert
- Opened up discussions with Medicines Authority who saw the value of investing in patient training and signed MOU to assist MHN in this.
- Patient representative appointed on the Appeal Board of the Pharmacy regulatory Body and Smoking and Health Advisory Committee.

Difficulties

- We evaluated the possibility of translating the whole site in Maltese Language but due to financial limitations, it did not allow us.
- In Malta there are very limited research and development studies and these are often carried out at University, need to strengthen relationship with University of Malta.
- Due to limited man-power although we would like to carry out training events using the mini-training material, so far opportunities have been very limited

EUPATI Tool box in Maltese

http://www.maltahealthnetwork.org/projects/european-patients-academy-eupati-patient-education/european-patients-academy-eupati-patient-education-toolbox-malti/