



European Patients' Academy on Therapeutic Innovation

<http://www.patientsacademy.eu> – info@patientsacademy.eu



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



- ▶ Launched Feb '12, runs for 5 years, 29 consortium members, PPP of EU Commission and EFPIA
- ▶ will **develop and disseminate objective, credible, correct and up-to-date public knowledge about medicines R&D**
- ▶ will **build competencies & expert capacity** among patients & public
- ▶ will **facilitate patient involvement in R&D** to support industry, academia, authorities and ethics committees



Project led by 4 key pan-European patient associations



- ▶ **European Patients Forum**
 - ▶ EUPATI Project Coordination
 - >50 umbrella patient organisations. Through 'members of members', potential outreach to 150 million patients



- ▶ **European Genetic Alliance Network**
 - Linked with national and regional patient alliances in Germany, Eastern Europe, Italy, Netherlands, United Kingdom and Ireland, Sweden, Spain, Italy, Greece and Balkan countries



- ▶ **EURORDIS – Rare Diseases Europe**
 - Representing >500 rare disease organisations in >45 countries



- ▶ **European AIDS Treatment Group**
 - More than 100 members in over 30 countries.

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

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



Within the next 5 years, the Patients' Academy will...



- ▶ **build expert capacity** by training patient advocates, and **competencies** among patients and the public
- ▶ **develop and disseminate** accessible, well-structured and user-friendly information and education on medicines R&D
- ▶ **create the leading public library** on medicines R&D: 7 languages, “creative commons” license
- ▶ **facilitate patient involvement in R&D** to partner up with academia, authorities, industry, ethics committees

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



Why do we need EUPATI?

In 2013, EUPATI set out to measure:

- Knowledge and awareness of medicines R&D
- Interest in learning more in medicines R&D
- Preferences for information formats and providers

7000 people were surveyed across 6 European countries [Spain, France, UK, Germany, Poland and Italy]



PUBLIC VIEWS ON MEDICINES DEVELOPMENT

Exploring attitudes, beliefs, knowledge and interest ACROSS EUROPE

In 2013, we asked 7,000 adults aged 18 years and over in select European countries about their attitudes towards, beliefs about and interest in learning more about the medicines development process as part of the groundwork for EUPATI.

RESEARCH PARTICIPATION



8%

CURRENT KNOWLEDGE

HIGHEST



1. Medicines safety 25%
2. Drug discovery 22%
3. Clinical trials 22%

LOWEST



1. Patients' roles and medicines regulation 18%
2. Medicines R & D 16%
3. Pharmacoeconomics 15%

INTERESTED IN LEARNING MORE



1. Medicines safety 50%
2. Personalised medicine 47%
3. Predictive medicine 47%

LESS INTERESTED IN LEARNING MORE



1. Pharmacoeconomics 33%
2. Medicines regulation 36%
3. Clinical trials and patients' roles 39%

INFORMATION SOURCES

TOP THREE



59%



59%



52%

BOTTOM THREE



15%



20%



21%

FAVOURED INFORMATION PROVIDERS

Doctor or other medical practitioner



70%

University / academic institution



41%

Patients' organisation



40%

LESS FAVOURED

Family member, friend or colleague



23%

Journalist or news organisation



20%

Public-private partnership



15%



EUPATI Research: public views of medicines R&D across Europe identified

- Low knowledge of R&D
- Poor participation in research
- Support for more information from patient organisations, academia and medical professionals

EUPATI Audiences: advocacy leaders and the public at large



EUPATI Certificate Training Programme

- Academic Modular Certificate Programme
- Patient Ambassadors & Patient Journalists raising awareness
- Patient Trainers for patient communities & networks

100
patient
advocates

EUPATI Educational Toolbox

- Educational tools for patient advocates
- Variety of distributable formats: Paper-based booklets, presentations, eLearning, webinars, videos etc.

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.
- Wiki, YouTube, films and/or cartoons

100.000
individuals



EUPATI Content: development timelines



Phase 1:
October 2014

EUPATI Certificate Training Programme

e-learning [150+hours]

classroom style face to face teaching

Two 4-day sessions Barcelona: April & Sept 2015]

Phase 2:
October 2015

Available:
2015

EUPATI Educational Toolbox

repository: video, webcast, pdf, presentation,
ebook, print ready material (booklets, pamphlets),
audio

Available:
2016

EUPATI Internet Library

WebPages
Streamed media
illustrations

English

English
French
German
Spanish
Polish
Italian
Russian

EUPATI PATIENT EXPERT TRAINING

COORDINATION



European Patients' Academy
on Therapeutic Innovation

EUPATI

Face-to-face

Forum

Glossary

You are not logged in. (Log in)

Welcome to the EUPATI moodle site

Course Overview	Discovery of Medicines and Planning of Medicines Development	Non-Clinical Testing and Pharmaceutical Development	Exploratory and Confirmatory Clinical Development
Face-to-Face Information	Clinical Trials	Regulatory Affairs, Medicinal Product Safety, Pharmacovigilance	HTA Principles and Practices

CALENDAR

May 2014

Sun	Mon	Tue	Wed	Thu	Fri	Sat
				1	2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	31

UPCOMING EVENTS

There are no upcoming events

[Go to calendar...](#)

LATEST NEWS

(No news has been posted yet)

**First course:
started Oct 2014**

**Second course:
starting Sept 2015**

EUPATI PATIENT TOOLKIT



Help | Font Size | Contrast



European Patients' Academy
on Therapeutic Innovation

Select your language: English



[Home](#) [About EUPATI?](#) [Glossary](#)

The A to Z of how medicines are developed

For patients and citizens by patients and citizens

Search our library of patient focused educational material

For example: How are drugs made?



Or browse our information library

From Laboratory to Patient	Making a Medicine	Effects of Medicines
Looking for new Medicine	Clinical Trials	Patient involvement
Laboratory Testing	Medicines Safety	Value of Medicines
	Medicine Approval	

**Coming soon:
Autumn 2015**

EUPATI PATIENT LIBRARY



EUPATI European Patients' Academy on Therapeutic Innovation

Home What is EUPATI About?

Patient Library

Search our library of patient focused educational material

E.g. Clinical trial, HTA, New cardiac treatments

Home > Patient Library > Discovery of Medicines

Basic Principles of medicine discovery and development

Download PDF Download ePub

Drug discovery
In the fields of medicine, biotechnology and pharmacology, drug discovery is the process by which new candidate medications are discovered.

History
Historically, drugs were discovered through identifying the active ingredient from traditional remedies or by serendipitous discovery. Later chemical libraries of synthetic small molecules, natural products or extracts were screened in intact cells or whole organisms to identify substances that have a desirable therapeutic effect in a process known as classical pharmacology. Natural product drug discovery.

Current techniques
Since sequencing of the human genome which allowed rapid cloning and synthesis of large quantities of purified proteins, it has become common practice to use high throughput screening of large compounds libraries against isolated biological targets which are hypothesized to be disease modifying in a process known as reverse pharmacology. Hits from these screens are then tested in cells and then in animals for efficacy.

Target Driven Discovery

Lead Driven Discovery

Lead Discovery
Biosynthetic, Virtual screening, Structure-based design, Screening, Hit-to-Lead

Development
Process Chemistry, Toxicology, Pharm Dev

Clinical Development
efficacy, Long Term Toxicology, Manufacture, Registration

★★★★ (1 votes, average: 1.00 out of 5, rated)

Share This Story, Choose Your Platform:

Glossary

Multilingual encyclopedia

Multimedia

Read or save content offline

Multilingual downloads and toolbox resources

Responsive library content for mobile devices

Coming soon:
2016

Areas covered by the Patients' Academy



1. Medicines development process from research to approval
2. Personalized and predictive medicine
3. Drug safety and risk/benefit assessment of medicines
4. Pharmaco-economics, health economics and health technology assessment
5. Design and objectives of clinical trials (& roles of stakeholders)
6. Patients roles & responsibilities in medicines development

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

EUPATI at the National Level – 12 countries



EUPATI NATIONAL LIAISON TEAMS are

temporary task forces of three members:

- 1) patients
- 2) academia
- 3) industry

Teams establish **EUPATI NATIONAL PLATFORMS**

- ensure EUPATI understands and responds to the educational needs at a national level
- disseminate EUPATI educational and training material to increase the number of patient advocates
- raise general public interest and media interest in EUPATI
- support national initiatives to encourage greater patient involvement in medicines research and development

UK
IE
CH
ES
FR
AT
DE
IT
MT
PL
LU
BE

EUPATI NLTs and ENPs



Country	Status	Major meetings
Germany		17 July 2013
Belgium		N/A
France		22 Feb 2012 21 Jan 2014
Austria		20 Oct 2014 Oct 2015
Malta		30 April 2014
Poland		19 Feb 2013

Country	Status	Major meetings
Spain		9 Jan 2012 4 Nov 2014
Switzerland		13 Jun 2013 4 Feb 2014 11 Dec 2014 25 March 2015
United Kingdom		18 Mar 2013 26 Sept 2013 6 March 2014
Luxembourg		3 April 2013 23 Oct 2013 17 Dec 2014 17 March 2015
Ireland		30 April 2014 16 Sept 2014
Italy		19 Feb 2013 14 Oct 2014 10 April 2015


Red: no NLT available

Yellow: NLT established, 1st meetings took place, 1st work in common has started

Green: NLT well advanced in preparing the establishment of the ENP

Implementing EUPATI at a national level

 The **UK EUPATI National Platform** meeting on 06 March 2014 attracted a fantastic response on social media with 12,000 tweets across Europe and even beyond, as well as a retweet by the Association of British Pharmaceutical Industries (ABPI) which has over 4000 followers!

 The **Irish EUPATI National Platform** meeting in Ireland on 16 September 2014 was supported by IPPOSI, the Irish Platform for Patient Organisations, Science and Industry with more than 400 members. National Radio personality and journalist, Aine Lawlor gave the keynote presentation during which she described her experience of clinical trials in her fight against cancer and stressed the importance of patient involvement.

 The **Italy EUPATI National Liaison Team** on 03 July 2014 signed a Memorandum of Understanding with the Italian Medical Agency (AIFA) to work together to maximise the number of Italian patients who are able to access EUPATI educational and training resources. On 10 April 2015, the Italian National Platform was launched in Rome at an event attended by more than 200 patient, academic and industry partners.

EUPATI NETWORK MEMBERS

A screenshot of the EUPATI website's registration page. The header features the EUPATI logo and the text 'European Patients' Academy on Therapeutic Innovation'. Below the header, there is a navigation bar with 'Home' selected. The main content area is titled 'Registration' and includes a 'Login' section on the left. The registration form itself has three input fields: 'Username or email' (containing 'Laura Kavanagh'), 'Password', and 'Verify Password'. Each field has a small icon to its right. Below the form, there is a small double colon icon. The page also includes a breadcrumb trail 'You are here: Home > Registration' and a paragraph of text explaining the registration process.

**** Access to EUPATI Network area**

**** Copies of EUPATI Newsletters**

**** Invites to EUPATI Network webinars**

**** Invites to EUPATI Workshops**

Register to join the EUPATI Network at
www.patientsacademy.eu

EUPATI NETWORK WEBINAR




Webinar – Enabling meaningful patient contribution to ethical review?



Our upcoming EUPATI webinar “How to enable meaningful patient contribution to ethical review?” will provide an opportunity to hear current experiences and expectations and to discuss your questions and suggestions on the **5th of March at 17:00 hours until 18:30 CET**.

You need to be a Network member to join in. If you already are, please register here.

If you are not yet a Network member (free and easy!), please sign up here.

Last Updated: Thursday, 05 February 2015 16:35 |  [Print](#)

1st webinar: 05 Nov 2014

2nd webinar: 05 Mar 2015

3rd webinar: May 2015

Further 2015 dates to be announced

EUPATI REGIONAL WORKSHOP



Save the date! – Our 2015 Workshop



- "Taking off on a national level – An interactive workshop on implementing EUPATI in your country"
- 22nd of April 2015 in Dublin
- How can you get involved – what is needed locally?

**22 April 2015:
Dublin**

**Travel and accommodation costs for registered network patient & academic representatives are fully covered by EUPATI

EUPATI LinkedIn Group



EUPATI Facebook Posts



EUPATI Twitter Tweets



@eupatients

- @EUPATI_Lux
- @EUPATI_UK
- @EUPATI_CH
- @EUPATI_ES
- @EUPATI_IT
- @EUPATI_FR



Patients' Academy

- EUPATI Spain
- EUPATI Luxembourg
- EUPATI France

Get to know us!



www.patientsacademy.eu

1200 Network members

1300 Newsletter subscribers

1300 Twitter followers
@eupatients / #EUPATI



900 Facebook friends



550 LinkedIn members

