Way forward & future topics
View from Patients and EUPATI

Jan Geissler & the EUPATI WP7 team
What is EUPATI?

- A Public Private Partnership within the IMI
- A 5-year project, launched in February 2012, ending January 2017
- A patient-led 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
- Developed and disseminate
  - 2x Patient Expert Training Course
  - EUPATI Internet Toolbox on Medicines R&D with 7 languages, 1 million words
Objective, credible, correct and up-to-date public knowledge about medicines R&D

- **EUPATI Patient Experts Training Course** -- for expert patients
  - 100 patient experts
  - 1st course completed, 2nd running

- **EUPATI Educational Toolbox** -- for patient advocates
  - 17,000 individuals in 3 months
  - 12,000 patient advocates

- **EUPATI Internet Library** -- for the health-interested public
  - Under development
  - 100,000 individuals

- **EUPATI Educational Toolbox** -- for patient advocates
  - 12,000 patient advocates

- **EUPATI Internet Library** -- for the health-interested public
  - 100,000 individuals

- **EUPATI Educational Toolbox** -- for patient advocates
  - 12,000 patient advocates

- **EUPATI Internet Library** -- for the health-interested public
  - 100,000 individuals

Languages:
- English
- French
- German
- Spanish
- Polish
- Italian
- Russian
EUPATI: A truly patient-led public private partnership

Project Steering Committee
(Project coordinator, 1 representative of each Consortium Partner)

Project Secretariat / WP1
EUPATI Director, Coordinator, Assistant, Communication Officer

WP2: Network Implementation
Patient-led National Platforms

WP3: Needs Assessment, Gap Analysis
Patient focuss groups

WP4: Content Development
WP co-led by patients, +authors, +reviewers

WP5: IT Infrastructure

WP6: Deployment & Quality Control
WP led by patients, user-testing

WP7: Sustainability
WP co-led by patients

Innovative Medicines Initiative Joint Undertaking

Regulatory Advisory Panel
EMA, BfArM, AIFA, Swissmedic, MHRA

Project Advisory Board
Cochrane, academia, ethics, media, patients

Ethics Panel

Coordinator is patient advocate, 5 organisations

Run by patient org

Co-led by patients

50% patients

Patient co-chair, PO members
EUPATI and involved organisations can contribute a lot to IMI2 in terms of...

- Governance
- Strategy and agenda setting
- Patient involvement in IMI projects
- Research topics aiming to implement patient involvement in medicines lifecycle

In more concrete terms:
1. Future topics for EUPATI
2. IMI2 patient engagement strategy
3. Potential future topics IMI2 (research strategy)
4. Financial considerations
1. Future topics that an EUPATI #2 may address: Advocacy & Strategy

- **PPI in R&D**
  - "How patients can engage in R&D" / Patient Advocacy capacity
  - “How to engage patients in R&D” (relevant stakeholders: academia, industry, regulators)
  - Matching advocates, opportunities and projects (two-way)

- **Addressing citizens, not only patients**
  - Health literacy
  - Primary prevention
  - Vaccination
  - Vulnerable populations

- **Innovation robustness**
  - Impact of innovation/technology on health systems
  - Move to an enabling HTA environment reflecting label changes
  - Better integrate technology and social & systems innovation
1. Future topics that an EUPATI #2 may address: Education and Training (1)

- Continuously update EUPATI material and adapt for toolbox use where appropriate

- Increase depth of existing E&T content topics:
  More specific information on certain topics - more vertical information
  - Expand HTA - illustrative national examples
  - Medical devices and their legislation
  - Personalised and precision medicine
  - Advanced therapies with ethical considerations
  - Conduct of international multi-centre trials
  - Develop optional module(s): in-depth content for specialist roles in regulatory committees
  - Expand coverage of biosimilars and generics
1. Future topics that an EUPATI #2 may address: Education and Training (2)

- Add disease/application-specific content in addendums (or optional modules)
  - Examples: vaccination, antimicrobial resistance
  - Link toolbox, specific application in a therapeutic area or disease

- EUPATI curriculum to cover R&D in
  - Future ventures – e.g. Public Private Partnerships
  - Financing models
  - Reinvestment in research

- Training for patients involved in (other) IMI projects
However, sustainability funding for EUPATI #2: Status Quo 2014-2016

True impact on patient involvement in medicines R&D will happen when
- we address the next, higher level of engagement, but also
- educate more patients/advocates post-2016 as base-level resource for the new stuff
  - EUPATI Patient Expert Training Course & corresponding network
  - EUPATI Toolbox www.eupati.eu in 79! languages
  - Support 12 16? EUPATI National Platforms

Committed industry funding: €170k/a for 3 years
Non-industry / public / private funding: €0
2. IMI Patient engagement strategy

- Patient involvement in IMI governance
  - Assessment of Short Proposals where appropriate
  - Recommendation to involve patients in consortia where impact expected (formulate call topic texts accordingly)
  - Patient involvement as a review criterion
  - Central advisory body, e.g. IMI Patient Advisory Committee
  - Patient representative on scientific committee, selected from central body

- IMI project results
  - Lay summary
  - Policy implications

- Case study collection
3. Potential future topics IMI

- Patient education towards participating in IMI2 consortia

- Points for consideration:
  - How can patients be involved in IMI projects?
  - How to communicate opportunities?
  - What are the gains for patients?
  - Sharing project information with patients
  - Identify content to update EUPATI material
3. Potential future topics IMI

- Patient engagement linking to existing EUPATI content and how to apply in, e.g.
  - Genome sequencing
  - Vaccines
  - Anti-microbial resistance etc.

- Collection and analysis of case studies where patients were involved incl. EUPATI case report forms to enable greater sharing of examples

- EUPATI ‘Patients Involved' page currently bridging a gap, to continue beyond EUPATI1 as a separate service outside of EUPATI, potentially run by patient groups in the future

- Horizon scanning for innovation with appropriate training materials for patients on identified topics to enable intelligence sharing
3. Potential future topics IMI

- More information for health interested citizens covering prevention activities
- Target low health literacy in populations
- Reflection on societal impact of innovative medicines on healthcare systems
- Outcomes research, big data, healthcare system robustness to pick up medicines innovation (access)
- Global dimensions and landscape of R&D,
- ICH structure, opportunity for pilot of global solution, co-funding patient involvement in ICH, partnership with countries, patient group involvement
4. Financial considerations

- Budget should be in place for umbrella patient organisations to consult and involve their members
- Compensation for the patient advocates in IMI committees
- Legal framework for paid involvement of patient advocates is difficult, e.g. CH law might need compensation for all external experts, also industry experts
You can help us to make patient involvement in R&amp;a success.

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