



Way forward & future topics

View from Patients and EUPATI

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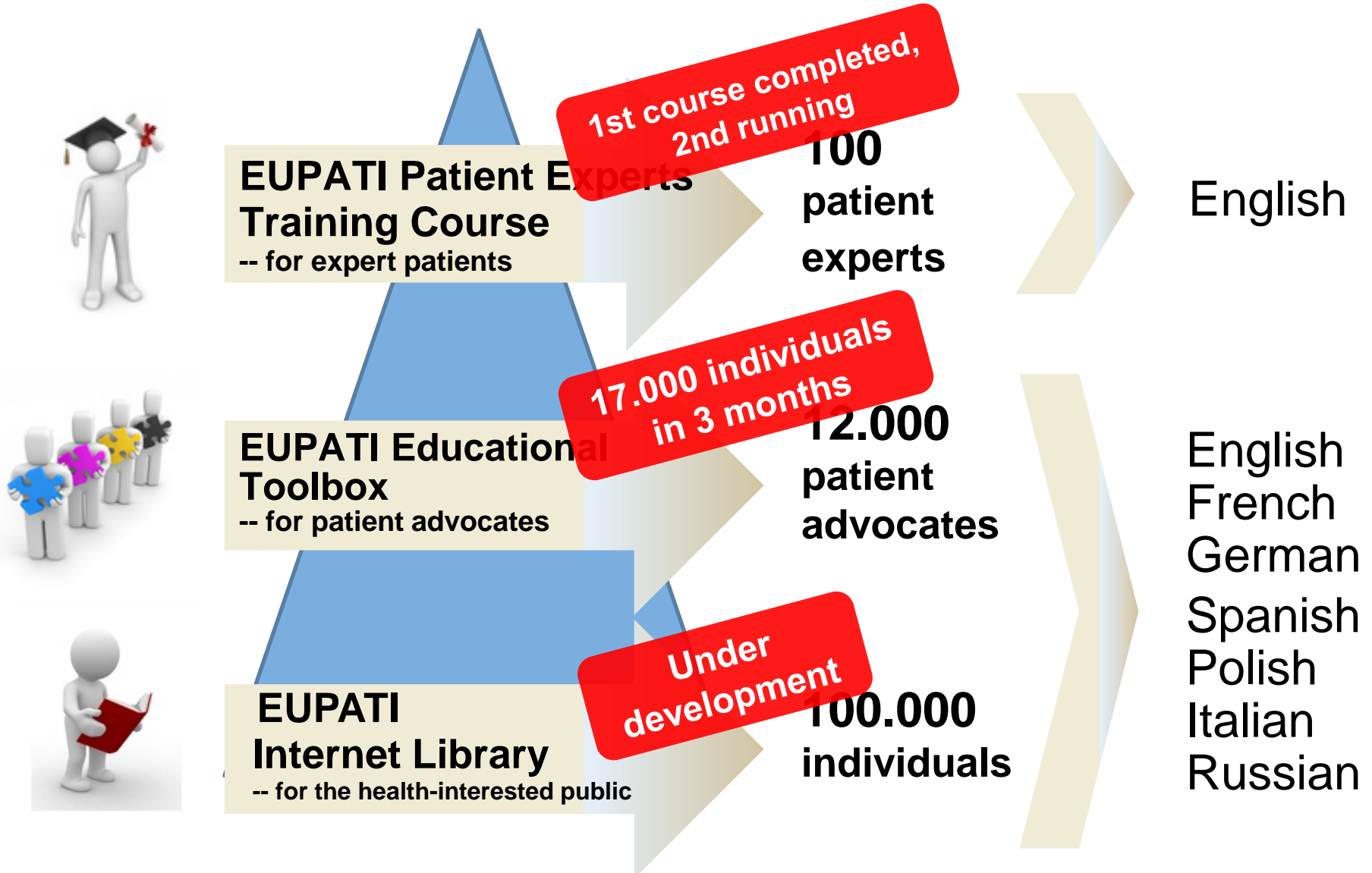


What is EUPATI?

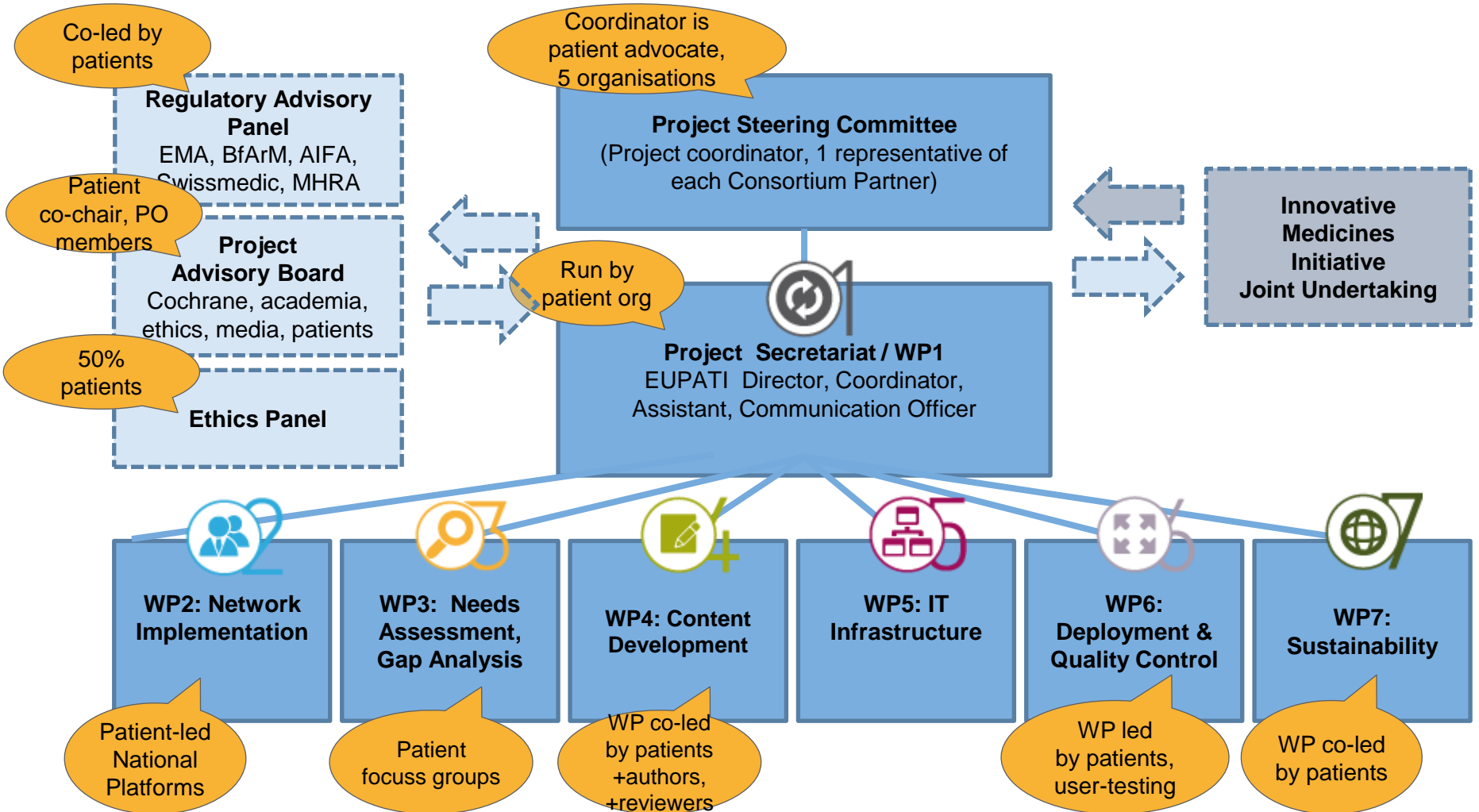
- **A Public Private Partnership** within the IMI
- **A 5-year project**, launched in February 2012, ending January 2017
- **A patient-led multi-stakeholder consortium** of patients' organisations, academia, NGOs and industry – 33 organisations
- **The key pan-European initiative** to build competencies & 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: A truly patient-led public private partnership



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

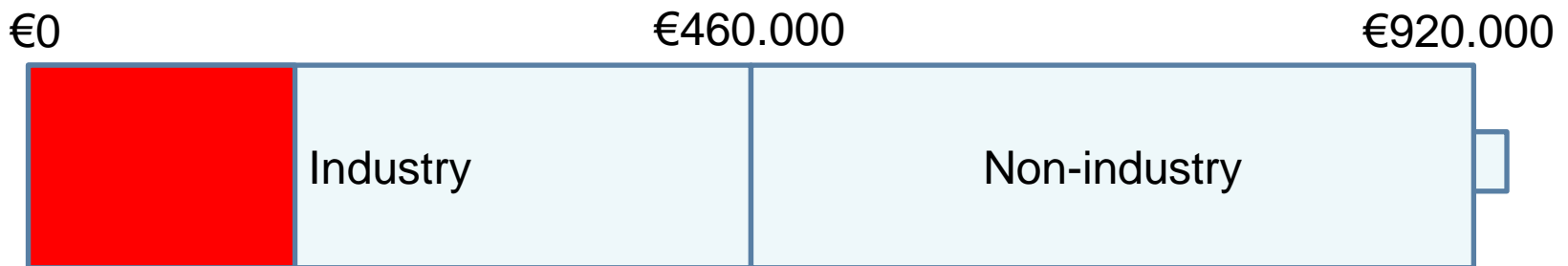
- EUPATI curriculum to cover R&D in
 - Future ventures – e.g Public Private Partnerships
 - Financing models
 - Reinvestment in research

- 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 7 **9!** languages
 - Support ~~42~~ **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&
a success.

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