EUPATI – Knowledge moves patients along the research process
Expert patients change the landscape and generate new knowledge together with other stakeholders.

Why patient education?

Knowledge production is influenced through active patient involvement

‘No one knows better what it is like to live with an illness day in, day out, than those who are – the patients and their family and friends who care for them.’

- Citizen science → community-initiated and -led research
  = systematic collection, organisation and publishing of evidence by patient communities
- No “alternative science” but an additional perspective
- Prerequisites:
  - sound methodological knowledge and application of rigorous, consistent scientific principles
  - Maintaining close contact and relationship with the communities of people living with or affected by an illness
  - Rethinking power relations in healthcare

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EUPATI achievements and results

Spanning the entire spectrum of biomedical research and development, EUPATI has produced practical results and a new paradigm of patient involvement.

- Toolbox used in 216 countries by 1,000,000+ individual users
- 96 EUPATI fellows plus 54 course participants, 4th course being planned
- Futures Group assessing and devising sustainability models
- 19 country platforms, 3000+ articles, 13 webinars, mini-courses, publications
- Guidance documents on patient involvement: Industry-led research and development, HTA processes, Ethical reviews, Regulatory processes

(published in peer-reviewed journal)
Impact

In addition to a growing network, publications and a theoretical framework, fellows also report profound changes in their roles as patient advocates.

<table>
<thead>
<tr>
<th>Role</th>
<th>Before</th>
<th>After</th>
</tr>
</thead>
<tbody>
<tr>
<td>Member of patient organisation, not actively involved</td>
<td>17%</td>
<td>2%</td>
</tr>
<tr>
<td>Active role in a patient organisation</td>
<td>62%</td>
<td>71%</td>
</tr>
<tr>
<td>Leadership role in a patient organisation</td>
<td>62%</td>
<td>71%</td>
</tr>
<tr>
<td>Employee of a patient organisation</td>
<td>25%</td>
<td>23%</td>
</tr>
<tr>
<td>Volunteer role in a patient organisation</td>
<td>60%</td>
<td>67%</td>
</tr>
<tr>
<td>Presenting at conferences, workshops etc.</td>
<td>63%</td>
<td>83%</td>
</tr>
<tr>
<td>Advising a pharmaceutical company</td>
<td>13%</td>
<td>44%</td>
</tr>
<tr>
<td>Advising a regulatory agency</td>
<td>21%</td>
<td>42%</td>
</tr>
<tr>
<td>Advising a reimbursement agency</td>
<td>4%</td>
<td>8%</td>
</tr>
</tbody>
</table>

EUPATI Fellows are increasingly taking leadership roles and are engaging with pharma, regulators and HTA bodies, and are more visible in events and conferences. Role changes also imply shifts in self- and public perception.

LIMITATIONS
- Sustainability
- IT platform
- Representation
- Transparency
- Professionalisation