

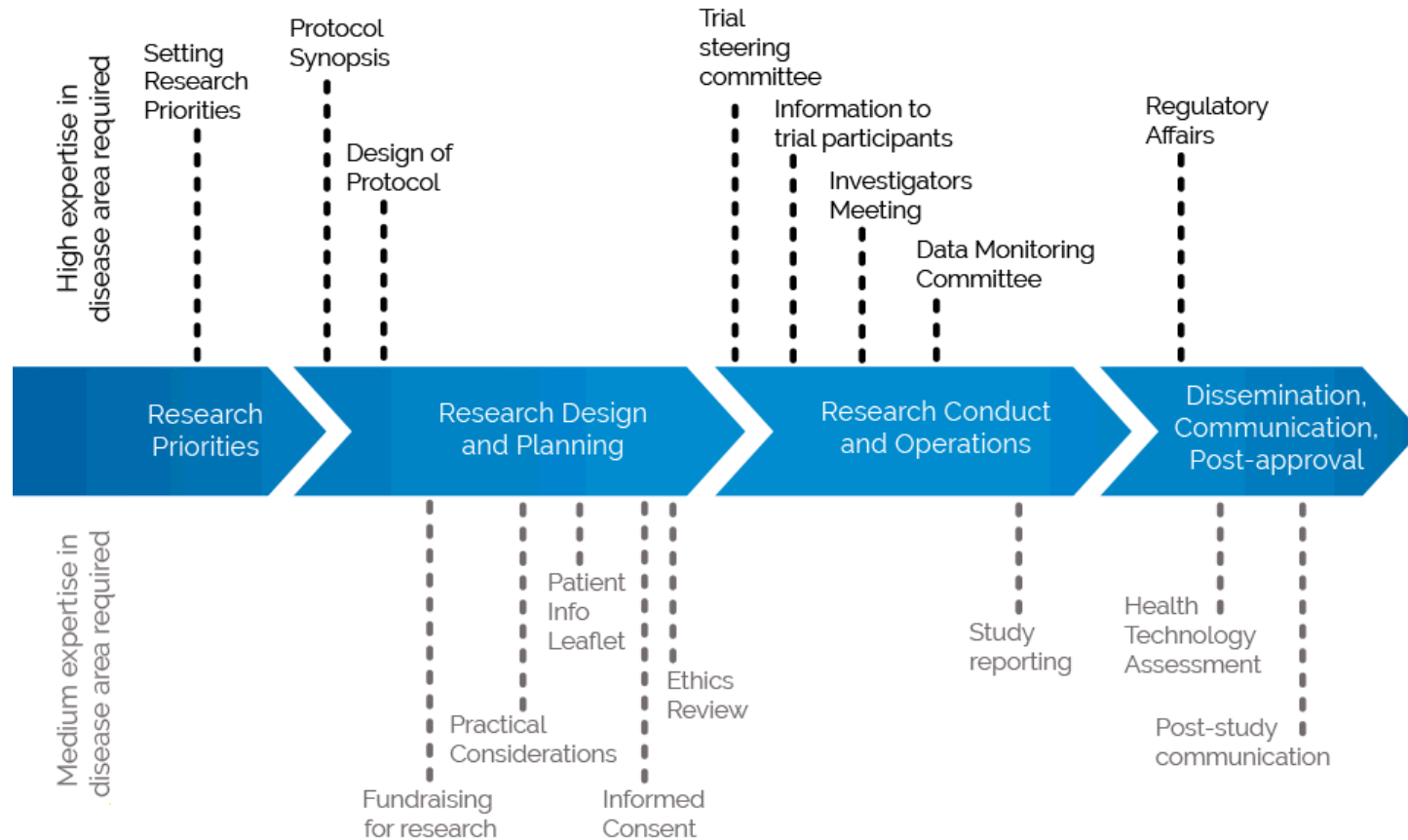
EUPATI – Knowledge moves patients along the research process

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Why patient education?

Expert patients change the landscape and generate new knowledge together with other stakeholders.



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

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 (published in peer-reviewed journal)
 - Industry-led research and development
 - HTA processes
 - Ethical reviews
 - Regulatory processes

Impact

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

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

LIMITATIONS

- Sustainability
- IT platform
- Representation
- Transparency
- Professionalisation

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.