

# REiNS Patient Representative Training

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NF Forum

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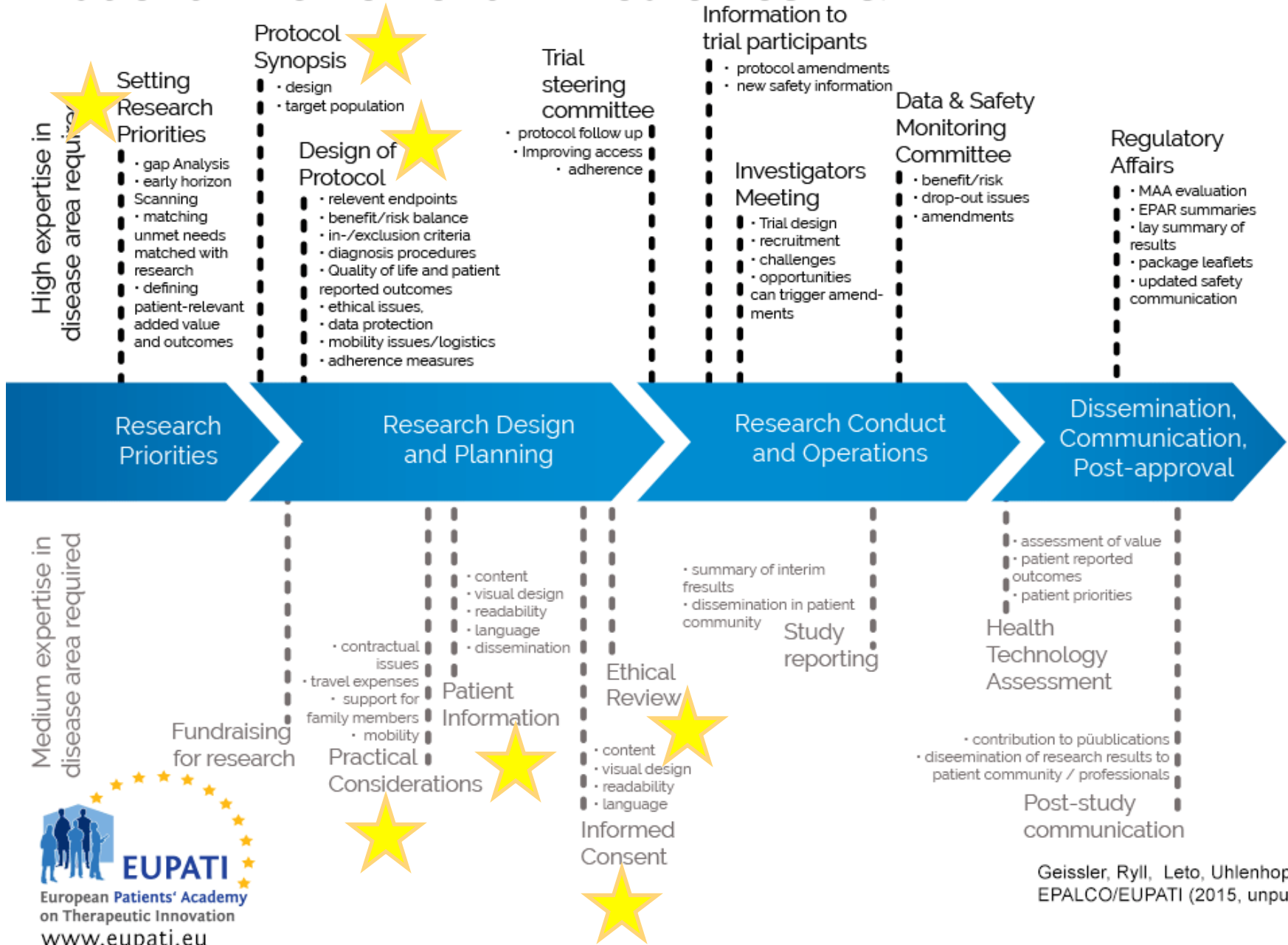
Response Evaluation In Neurofibromatosis Schwannomatosis  
INTERNATIONAL COLLABORATION

# Patient Engagement in Study Development and Design

- Extremely important!
- Key Benefits:
  - Increased relevance of clinical trial
  - Meaningful trial endpoints
  - Unique perspective on benefits/risks
  - Community engagement/recruitment



# Patient involvement in medicines R&D



# Potential Barriers to Patient Engagement in Study Design

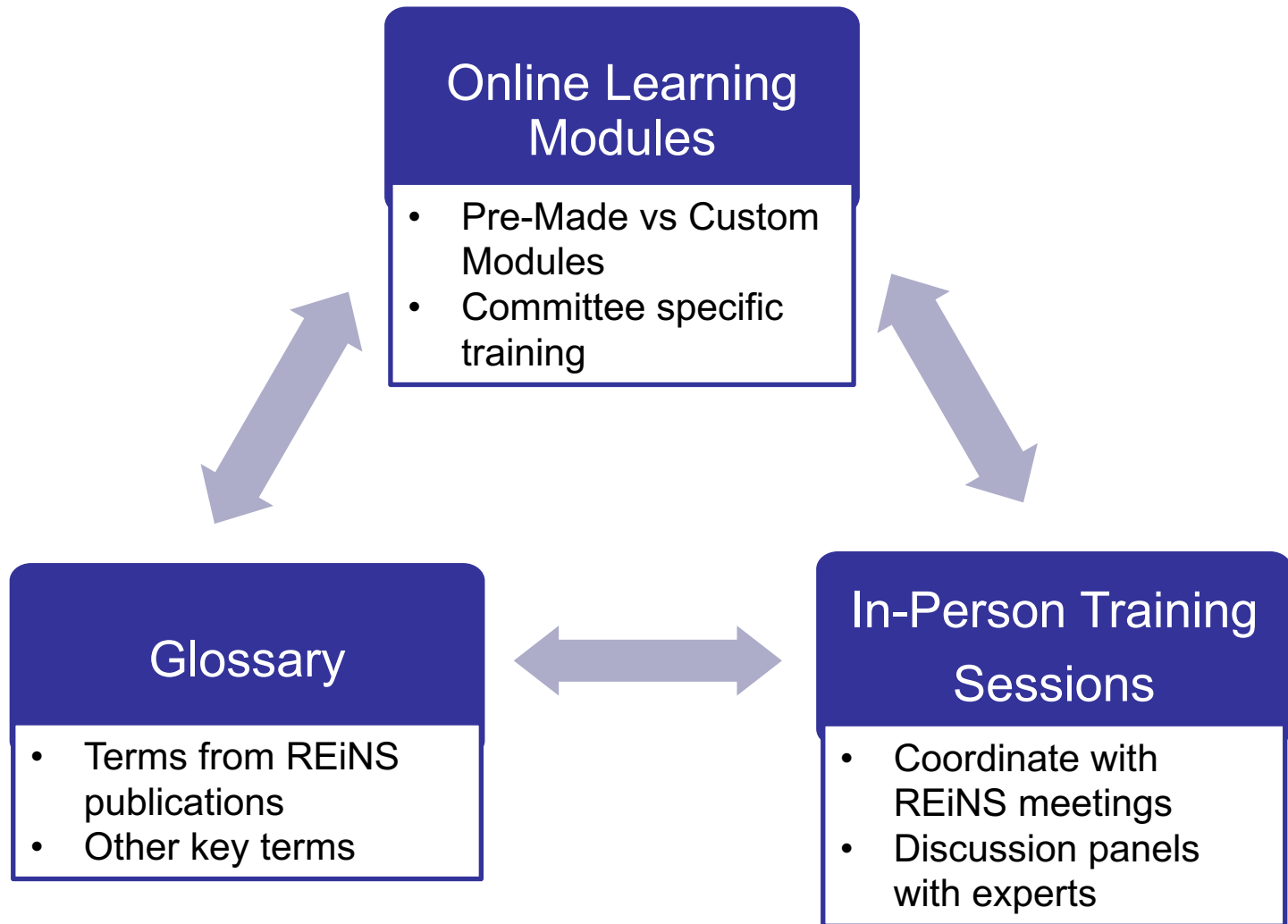
- Patients interested in participating in the process
- Researchers open to working with patient representatives on study design
- Education for researchers about importance of patient engagement
- Education for patient representatives about protocol and study design methods

# Key Components of Patient Representative Training

- General Background:
  - What is a clinical trial?
  - Clinical trial design
  - Terminology
  - Ethics of clinical research
  - Methodology
- NF/Schwannomatosis Specific Information

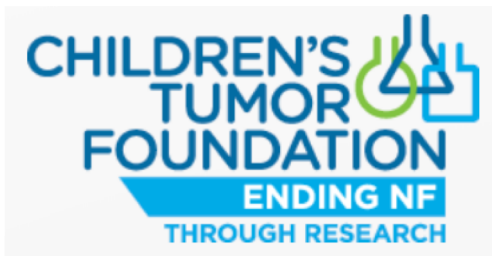


# Proposed REiNS Patient Representative Training Paradigm



# Ongoing Challenges

- Online Modules
  - Accessibility of content
  - Applicability to NF/Schwannomatosis
  - Determining number and content of "required" modules



- In-Person training Sessions:
  - Determining topics
  - Relevance to all patient representatives



***THANK YOU*** to the REiNS Patient  
Representative Education  
Subcommittee:

- Dale Berg
- Barbara Franklin
- Scott Plotkin
- Claas Röhl

...and many others who have contributed  
ideas and have volunteered to help  
moving forward!





# Any Questions?

