



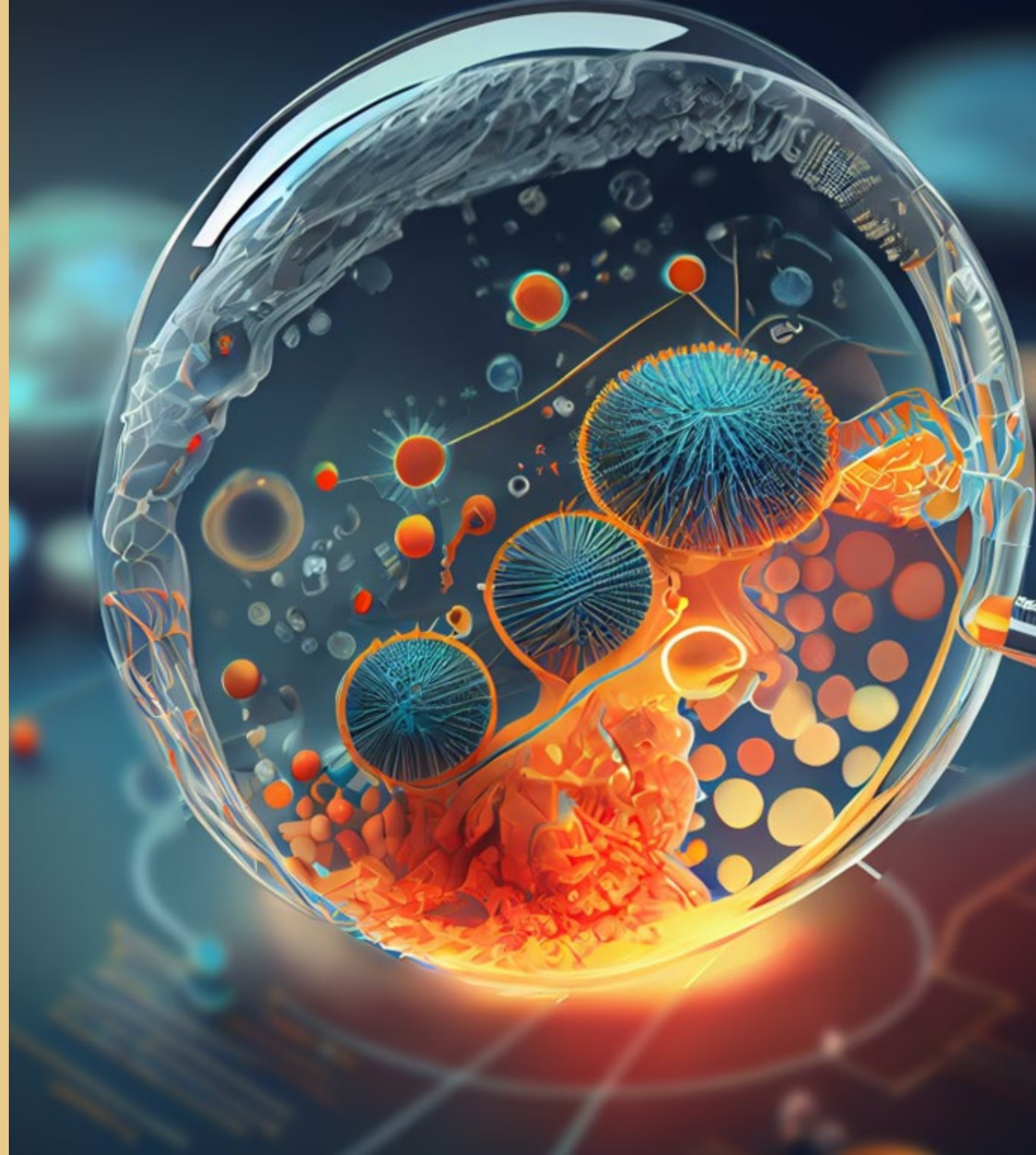
Access to precision medicine: the patient advocacy perspective

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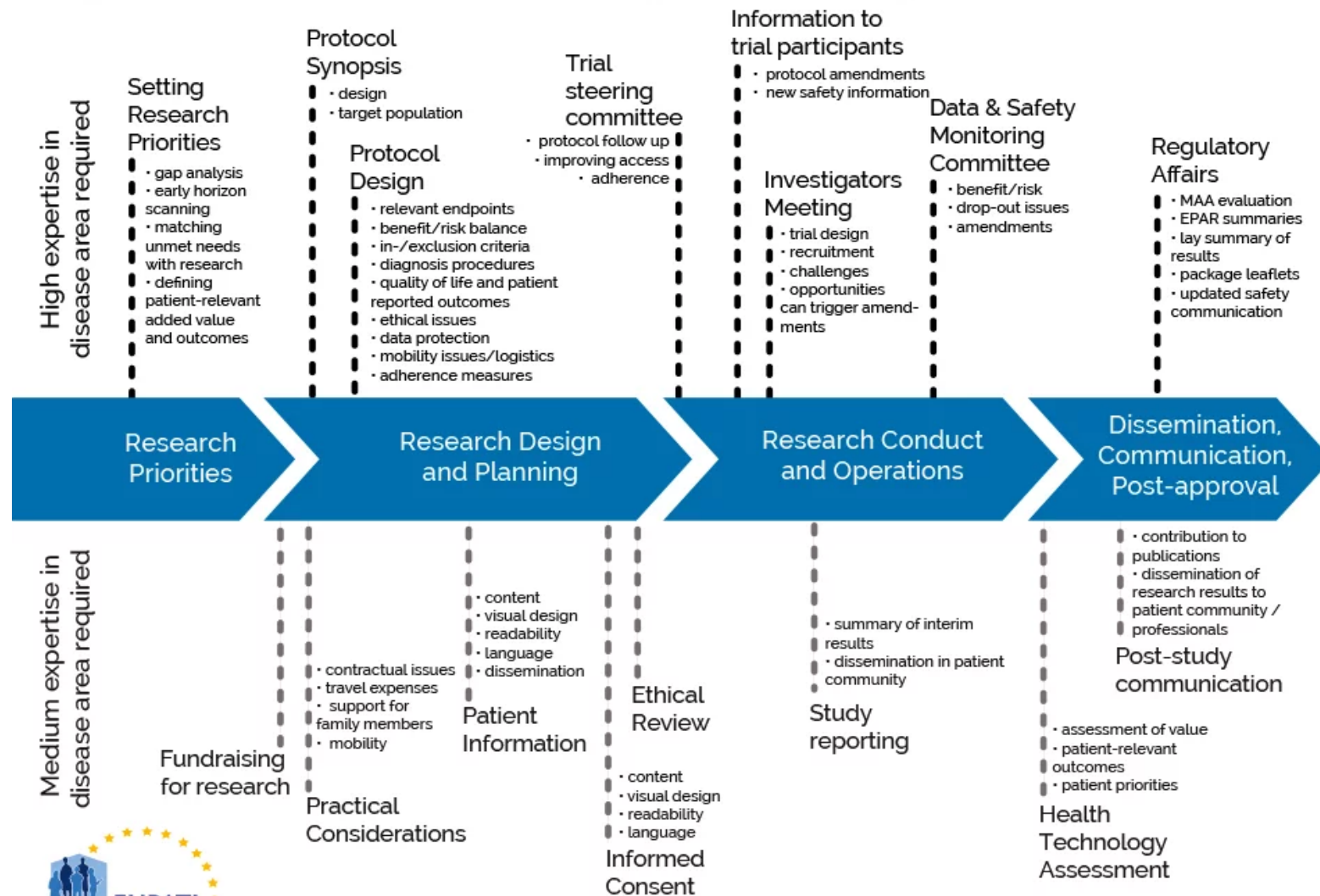


The BMJ champions patient partnership to help doctors make better decisions in PM



- **BMJ strengthened patient partnership** starting in 2014 by developing internal expertise, introducing patient editors, and requiring research to include statements on patient and public involvement.
- **Significant adoption of patient and public review:** By 2022, **over 85% of research papers** underwent patient and public review, with around 50% of accepted research having completed this process. (I've conducted several patient reviews over last seven years.)
- **Focus on patient involvement in genomic medicine:** In 2023 after patient safety, the second highest priority **was patient involvement in genomic medicine**. (see Doble et al. 2023, *BMJ*)

Patient involvement in medicines R&D



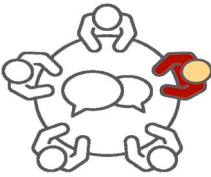
Geissler, Ryll, Leto, Uhlenhopp
doi: 10.1177/2168479017706405

EUPATI European Patients' Academy for Therapeutic Innovation created an Open Classroom where content is free for all learners learning.eupati.eu

The same potential patient involvement can be charted along the care and clinical continuum to improve access to and the effectiveness of **precision medicine.**

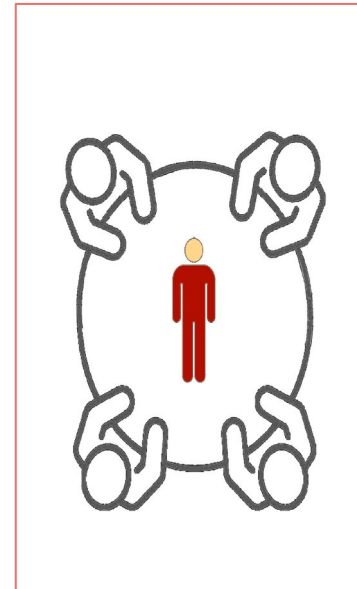


Patient education for better patient involvement



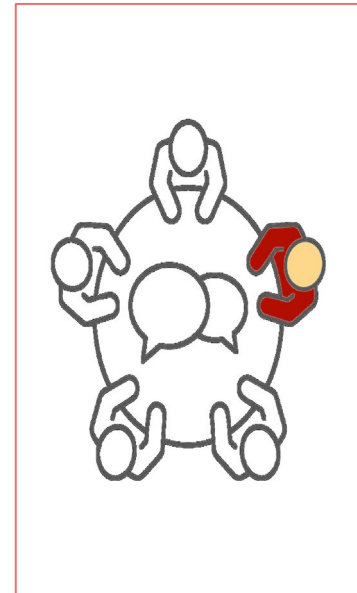
Education platforms such as EUPATI:

- Online toolbox: For patient advocates and the public
- Patient expert training course: for expert patients to be effective partners to industry, clinical research, regulatory bodies and the health authorities.
- Training patients towards a better understanding on patient engagement, partnerships and collaborations with other stakeholders.
- EUPATI “fellows”: Accredited; matching services
- Patient organizations provide recommendations



Patient
centricity
to
patient
involvement

*Patient
partner –
a value
stakeholder*



Addressing Health Equity – Advocating for All Patients

- **The Need for Inclusive Access:**
Address disparities in access to precision medicine based on socioeconomic status, race, and geographic location.
- **Patient Advocate’s Role as both educators and agents of Policy and Systemic Change:**
Advocates not only educate individual or groups of patients but also push for broader policy changes that make precision medicine more accessible to all.
- **Collaboration with Healthcare Systems:**
Advocates can work with healthcare providers, insurers, and policymakers to remove barriers and ensure equitable access to precision medicine.

💡 SCCL has a weekly MTB, video-conferenced, bringing together specialists from the academic and the private sector but no patient representatives.

💡 SCCL sees around 400 cases per year vs MarieCurie Paris ~ 250 cases per year.

💡 Liu et al. 2023 a small Texas MTB, consisting of pediatric oncologists, pathologists, and pharmacists, evaluated 115 cases between 2016 and 2021. Only 3 patients, however, received MTB targeted therapy, and only 1 of demonstrated an improved clinical outcome.

💡 *European Molecular Tumour Board Network (EMTBN)*, e.g., physicians, scientists, **patient representatives**, ethicists

Takeways:

- Patient involvement could help with raising awareness of the benefits of biomarker testing and precision medicine with patients and health stakeholders.
- This could lead to improved patient outcomes through optimal treatment for each person
- More targeted therapies could reduce ineffective treatments and lead to long-term savings on healthcare budgets.

Questions

1. Do you know of MTBs that include patient involvement in any way?
2. What is your reaction to the idea of involving patient advocates?
3. What kind of background or experience would you want to see in such patient advocates?
4. What value do patient advocates bring in terms of educating patients and other stakeholders?
5. How do you view the need to research etiology and causation and emphasize prevention vs medicines development?