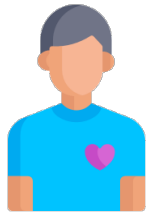
How can patient organizations contribute to the successful implementation of the CTR, and what does success look like?

2 main ideas

PROMs are crucial, the source is the patient

Promote natural histories implementation. We must support patient registries managed by patients



PROMs are crucial, the source is the patient

- Patient should be recognized like the main source for PROMs
- Patients' organization should take this responsibility and make sure the PROMs are owned by them
- Regulatory bodies should provide the tools to express this need, capture the information using standards and make sure the information is accessible and available
- We can’t leave patients alone with this task
- Empower patients mean empower patients with data

Promote the use of registries managed by patients. Some problems to solve

- Data Quality and Consistency: Patients may lack the knowledge or tools necessary for accurate data entry.

- Privacy and Security Concerns: The management of sensitive health information by non-professionals raises questions about data privacy and security. Patients might not be aware of or may not adhere to regulations like GDPR, potentially causing data breaches or misuse.

- Technical Challenges: Patients might lack the technical expertise needed to set up and maintain a digital registry.

- Representativeness and Bias: Patient-managed registries might not be representative of the broader patient population as they can be biased towards those with better access to technology and higher health literacy.

- Legal and Ethical Issues: Patients might not be aware of the legal and ethical aspects of data sharing and consent. This may lead to unauthorized use of data or not obtaining proper informed consent from participants, which can have legal repercussions.