

A patient and care-giver guide to healthcare intervention research beyond clinical trials:

What is it and why should I get involved?

Healthcare intervention research beyond clinical trials is often termed **Health Economics and Outcomes Research (HEOR)** and brings together:

- **Health Economics:** measuring and valuing the impact of healthcare interventions
- **Outcomes Research:** studies that evaluate the effect of healthcare interventions on patients with measures that are meaningful to them and their care-givers

The ultimate objective of HEOR is to supply data and insights to improve healthcare decision-making and help patients access new treatments and interventions. Given this, **HEOR isn't just for scientists – it's part of your or your loved one's story so why not be part of the process.**



Why is this a relevant topic for patient communities?

There is a growing recognition of the value of partnering with patient communities in improving Health Economic Outcomes Research processes. By involving patients, better research can be conducted which can in turn lead to faster and improved access to new treatments for patients. In summary, if we can work together and develop collaborative partnerships between pharmaceutical companies and patient communities, we can generate opportunities where everyone can benefit from improved HEOR processes.

Why is it important for patient communities to contribute to HEOR processes?

Understanding what realistic expectations we can have of patients and their care givers when it comes to their involvement in research studies (e.g. time involved in the study, travel, emotional impact of participating in a study)

Identifying the moments that matter the most to patients and their families, and what needs to be measured in order to generate evidence that a new treatment is beneficial and valuable to them from a quality of life perspective

Decision makers (often called Healthcare Technology Assessment (HTA) bodies) increasingly want to hear directly from patients when making decisions about whether to fund a new treatment. There are also HTA mandated healthcare intervention research studies that help improve the safety of medicines when treatments are introduced

Translating research data into information that is meaningful for patients and their healthcare professionals to enable improved communication, better informed consultations and, ultimately, shared decision making

How can patient communities contribute to HEOR?

Intent to improve outcomes

Be open to collaborating with pharmaceutical companies, acknowledging that their intent is ultimately to improve patient outcomes through their HEOR processes

Involvement at every step

When engaging with pharmaceutical companies be proactive about highlighting where you believe your patient community can add value and be clear on reasonable time and travel commitments

Inspired by the moments that matter most

Be willing to share experiences and journeys towards and beyond diagnosis that will help researchers ensure they collect data that demonstrate value to you and society as a whole

Informed through thoughtful communications

Collaborate with pharmaceutical companies to ensure that when information about studies is shared it is understandable for your patient community

Scientists and researchers are striving to collaborate with patient communities to make HEOR more accessible to all. With your help they can make it even more so! By working together, we can improve HEOR processes leading to better data and informed decisions towards the availability of new treatments.

By participating in HEOR we can all be part of the story to improve our health outcomes.