



Patient engagement: What is it? And why is it important?

Louise Veltrop-Duits

Central Committee on Research involving Human Participants (CCMO) – the Netherlands

Oversight Officer / project manager patient engagement



What is patient engagement?

- Patient engagement, participation, involvement, empowerment
- Patient engagement entails making use of patient-specific expertise for anything that may improve healthcare
 - projects for healthcare design and organisation, quality of healthcare, research, education, policy or innovations
 - Patients: patients, clients, their loved ones, next-of-kin, representatives or healthy volunteers



What does patient engagement not signify?

Patient engagement is NOT the same as participating in a clinical trial



There are many different types of patient engagement



Types of roles and activities during the research process

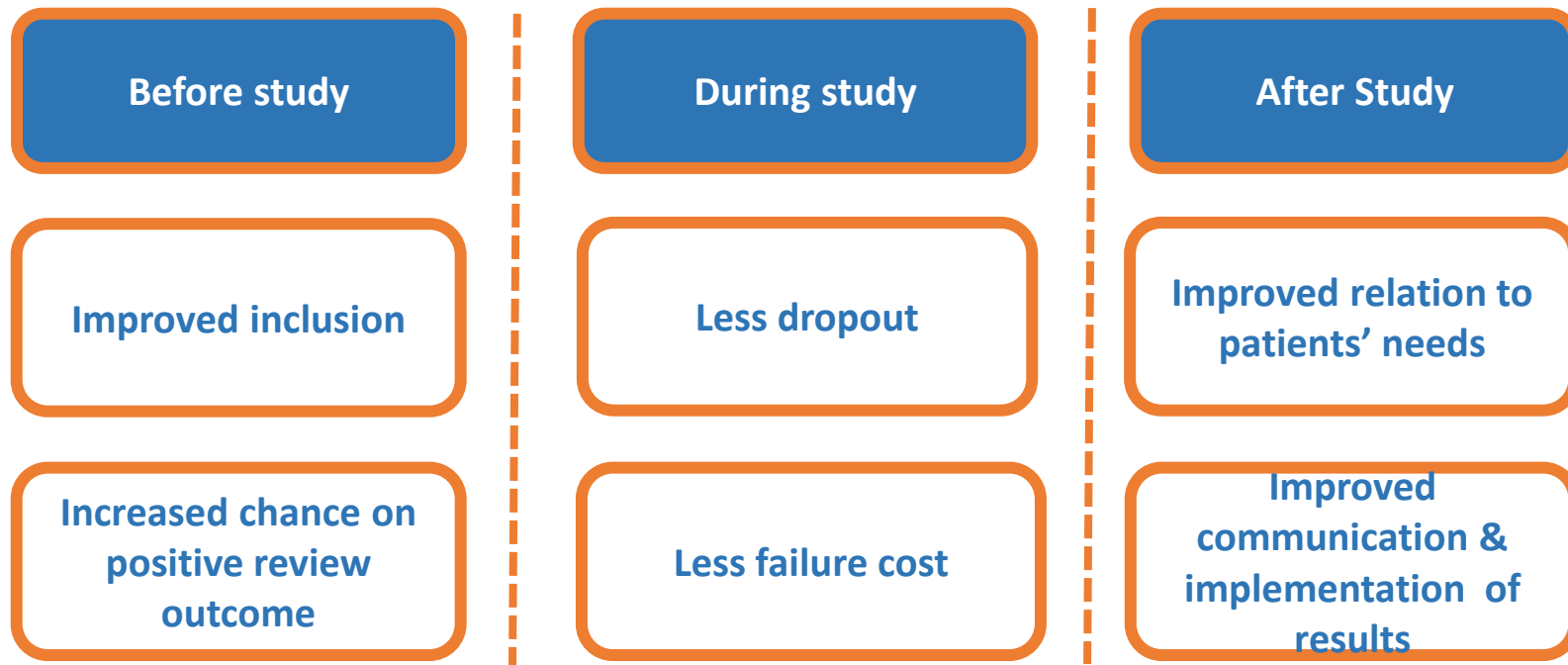


Picture: Patiëntenfederatie

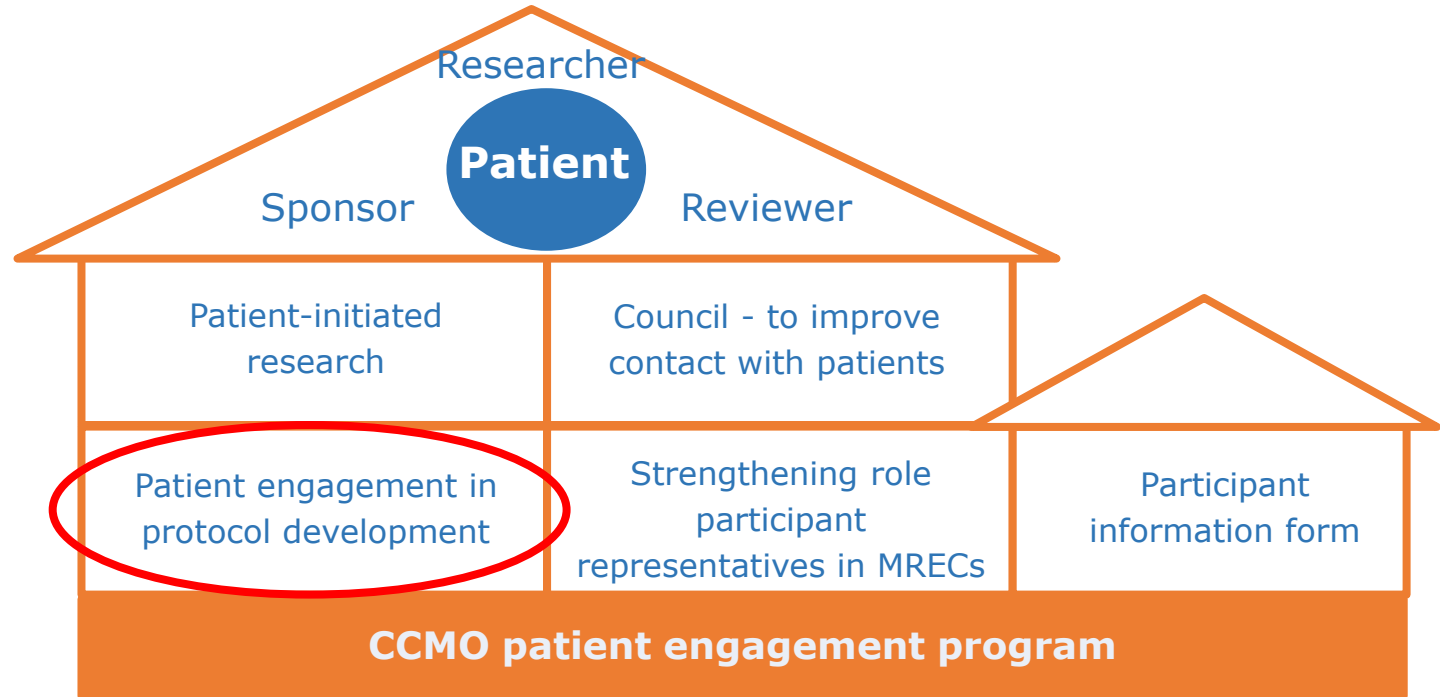


Picture M.de Wit, et al

What are the advantages of patient engagement?



ccmo - Patient-engagement programme



Patient engagement in development of research protocols

- For national non-CTR studies, the sponsor has to answer questions on patient engagement in research protocol
- Indicating the amount of patient engagement is obligatory, patient engagement is not. But the choice for not involving patients must be motivated.
- Creates awareness
- Next steps: implementation for multi-national studies & evaluation

Minimal attention to patient engagement in CTR protocols

Any questions

