

# RISK AND BENEFIT ASSESSMENT

## Group 5. Who and how should we educate patients (which patients) willing to be in steering committees in trial design and evaluation of clinical trials?

1. Every body brings in their own perspective , is education needed?
2. Basic knowledge about trials can help to be more effective in your communication
3. There are organisations (Eurpati) who help patients to understand trials (European Patients Academie on Therapeutic Innovation)
4. ESC Patient Forum gives guidance and mentor in the ESC guideline process, but does not think specific education is needed
5. Involve patients from the start so the patient also grows in the trial and guideline (the time line)
6. Difference input between patient experts and patients
7. Patients should not be overloaded and get a good explanation of expectations
8. Important who educates patients
9. Input of patients can be different in different phases of trials and guidelines and market research might be needed to find the 'best person for the job' and avoid bias
10. Other 'ways' of patient involvement are possible (e.g. reflections online, interviews, have them in the panel)

Patients and the public can be involved at all stages of a research project. This graph of the research cycle illustrates the different stages of a research project, and examples of how they can be involved

## Involvement round the research cycle

