



Who is the leaflet for?

Anyone involved in research

Why is it needed?

Patients are the end users of health research; however, they are still rarely involved in the design of health research.

Some useful tips:

- If not already doing so, adapt your budget where possible to include expenses and travel payments for research participants
- Think about scheduling research participation sessions around work and school timetable

Researchers should involve patients in research design as it will:

- Result in better/more accurate research outcomes
- Brings the patients perspective into research
- Benefit patients themselves
- Maximize partnership and avoid exploitation
- Benefit the support of patients for scientific studies and research as evidence of patients being involved in research design often required by research ethics committee



How to involve patients in research design

- Develop a good relationship with the patient association in your country
- Treat them as a partner rather than just a gateway to a population of potential research participants
- Conduct focus groups of participants to help design your research
- Invite research partners/lay members on research committees or as reviewers
- Get them to review and approve patient information
- Check with the patient representatives that the language and meaning is understandable
- Makes sure that information is as clear as possible, in order to decrease dropout the commitments required of a research participant must be clear.
- This will ultimately improve your research!

Questions to put to researchers:

- Think about **why** you are doing your research
- What are the most important research questions **for the patients**?
- What are the **benefits** of this research to the patients, are they clear to the patients?
- What do the results **mean** for the participants?

Take home message

By following the advice in this leaflet you will find:

- Benefits to yourself – the researchers
- Better research outcomes
- More participants
- More research engagement
- Better ethics committee to your applications when patients have been involved in your research design

Many thanks to:

Seonaid Anderson, Gary Heiman, Chaim Huijsers & Veerle Jacobs. The ESSTS board and the ESSTS TS support organisations.