

Patient engagement checklist for researchers

Collaboration with patients and patient organisations increases the quality of research. The experiences and opinions of patient representatives should be used at different stages of the research process. A member of a research panel, a representative of a patient organisation or an individual patient can be involved in research activities from the design of the study to the publication of the results or can be involved in a single task related to a specific stage of the research process. The aim of this collaboration is to enhance the impact of the research.

The study can be submitted for early review by patients, for example, through a patient organisation or to a research panel at a university hospital. Comments can also be requested on individual research questions.

At least the following points should be taken into account in the study:

Have patients' perspectives been taken into account

- when selecting the research topic?
 - in the study design?
 - in the research question?
 - in the choice of research methodology?
 - in the feasibility of the study?
 - in the patient recruitment process?
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- Are the information leaflets, cover letters, consent forms clear and accessible, and concepts explained in a way that is understandable to the layperson?
 - Have ethical issues been considered from the patient's perspective?
 - Are patients' rights clearly explained?
 - Is participation in the study too burdensome from the patient's point of view? (number of visits, documents to be filled in, patient diary, etc.)? / How burdensome is it for the patient to participate in the study (number of visits, documents to be filled in, patient diary, etc.)?
 - Does the researcher have a plan to communicate the results of the research to the research participants and the general public (scientific communication)?

Sources and more information:

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Chalmers I ym. How to increase value and reduce waste when research priorities are set. *Lancet* 2014;383:156–65.

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Richards T ym. Better together: patient partnership in medical journals *BMJ* 2018;362:k3798. doi:10.1136/bmj.k3798

WHO (World Health Organization) Collaborating Center for Research and Training in the Patient Perspective on Medicines Use. <https://whocc-meduse.ku.dk/>

Appendices:

Picture 1. Why should a researcher in rational medicine use collaborate with patient organisations?

Picture 2. As a researcher, how can I develop collaboration with patient organisations?