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International call for better local treatment
of rare and/or hard-to-treat cancers



Guidelines on Patient Centricity & Patient Involvement

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These guidelines form the instructions on how to write a project proposal for the patient advocacy committee (PAC). The guidelines are focused on patient centricity and patient involvement. Patient centricity signifies the focus of the project being on the need and wishes of patients, whereas patient involvement indicates the active involvement of patients and/or patient organizations in the study design, the conduction of the research, and the communication of the results to the patient community.

Application Form

- Be objective and honest in your application. Ensure that your application for the PAC is in accordance with your application for the scientific expert committee (SEC).
- Bear in mind that the PAC will only review the “PAC application form”.
- Be aware that your application for the PAC must be in layman’s language and make sure that used jargon is explained.
- Use clear argumentation with a logical structure.
- Make use of clear figures and diagrams to support your text.
- Your applications for the PAC will be read and reviewed by patients; therefore, we advise you to involve one or more patients/patient organizations in proofreading your application before applying. Actively ask them for suggestions regarding content and language.

Patient Centricity

- Pay sufficient attention to explaining the need of your research and the added value for patients. Address the question ‘Did the demand for this research come directly from the patients of the target group?’. If so, explain the conversation you had with these patients.
- If the application is a follow-up of the results from (a) previous study/studies, please elaborate on the status and the results of this previous study. Explain in which way the previously gathered results will add value to the current proposal.
- Explain the choice for the used inclusion criteria for study participants
- Elaborate on the expected process after the project. Think about questions like: Will there be a need for a follow-up study? Will the treatment be practically feasible? Will the treatment be available for a wide spectrum of patients? Is contact already made with other centres?
- Explain the possible burden and benefits that patients can experience by participating in the study. Keep in mind that effects in quality of life are equally as important as effects in life expectancy. Pay attention to the follow-up of both physical and mental side-effects during the study.
- Explain the cost-benefit ratio for participants. Do the expected results outweigh the burden and risks? Did you consult patients in the evaluation of the cost-benefit ratio?
- Clearly explain the interventions and steps that participants will undergo in the process and make sure the burden for participants is minimized as much as possible.
- Explain the communication and dissemination plan of the results among the patients.

Patient Involvement

- Actively involve patients in your research by reaching out to a patient association from the start of development of the trial. Actively involve them during the whole trial process (the preparation of the project, the conduction of the research, and the dissemination of the results). Where passive involvement includes informing patients, active involvement indicates a form of co-creating and forming a substantial contribution to the research.

- Does your trial concern a small group of patients of which there is no patient association? You can still actively involve patients by approaching patients (that are not part of a patient organization) and ask them to collaborate and give feedback on your research. You can also involve ex-patients or their close relatives.
- Pay attention to informing participants about (interim) results.
- Pay attention to the wide-spread dissemination of the study results. Point out which steps you are going to take to reach as many patients as possible and which media you are going to use for this.
- Make sure you explain your patient involvement in a concrete way: elaborate on your already made steps and the steps you are still planning to take. Think about: In which way did/will you collaborate with patients? Who are these patients? In which phases of your research will you involve patients? Which questions will be/where asked to these patients? How will be/was this feedback implemented? How are you planning to disseminate your results to participating patients and patients of your target group?