

INFORMATION ABOUT PATIENT PARTICIPATION IN RESEARCH AND GUIDELINE DEVELOPMENT

For anyone applying for a grant for scientific research.

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When applying for grants for medical scientific research, it is becoming increasingly compulsory to involve a patient organisation in the application and implementation of the research. It is often unknown what patient organisations can do in this respect and what to do if there are no patient organisations in your country. This article contains advice and guidance on what the patient organisation can do. Do not hesitate to contact me or my colleagues for more information.

Introduction

Patients increasingly play an active role in care, policy and research. And that is not without reason. Practice shows that patient participation really does have an added value. Many institutions that finance scientific research require cooperation with a patient organisation or the involvement of patients in a patient panel. They also often ask to describe their input and role. It is increasingly compulsory to involve patient organisations or panels in scientific research. Applications for funding require patient organisations to be involved in the project organisations, include them in the budget plan and in any case a letter of support is needed with the application. Finally, involvement of patients can be useful when implementing results of a project.

This document provides insights into the how and why and gives advice on how to deal with patient participation in research applications for funding.

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1. Background information about patient participation

Patient participation is a broad concept. It concerns experiential expertise that can be deployed in various ways and at various levels like contributing to scientific research, contributing to guidelines, protocols and quality standards but also contributing to a conference by giving a presentation or participating in focus groups.

1.1 Four good reasons for patient participation

1. Complement: the unique experience or 'hands-on' expertise of patients complements the knowledge and experience of other parties in healthcare, such as healthcare providers, scientists and policymakers. Bringing together this different knowledge and experience can lead to new insights. It can also, for example, increase the relevance and quality of a project, research or innovation.

2. Meeting the needs of patients: patient participation ensures that developments in research, policy, guideline development and care innovation are better attuned to patients' needs and expectations. It also provides insight into what patients and their relatives consider feasible and acceptable, for example when dealing with potentially controversial or sensitive issues or intensive treatment.

3. Contributes to implementation: patient participation in all phases of a project or research also contributes to its implementation: that something is done with the findings. Think of more and better communication about the results. A patient organisation or patient representative can certainly mean a lot when it comes to reaching patients.

4. Value for the patient: patient participation can also be of great value to the patient. And not only the patient, but of course also any relatives who act as patient representatives. Think of knowledge of the latest insights in healthcare, satisfaction through making a valuable contribution, developing new knowledge and skills and making contacts with parties involved in healthcare. Being active in a patient organisation can be fulfilling and inspiring in many ways.

1.2 Difference between experience patient experts, patient representatives and patient advocates

Patient experts can help improve the quality of care and the quality of life. Patient experts are patients with the diseases and know about unmet needs, treatment etc. They are very valuable in identifying unmet needs and patient journeys

Patient representatives* can support contact with patients participating and act various consultations.

Patient advocates* are professionals (often paid), the ones who lobby and are a full discussion partner in the whole process, from the very beginning to the end. They are the bridge between patients and scientific researchers. They may also bring a patient perspective on research activities to scientific advisory boards and committees. They monitor the context, the procedures and patient participation.

*To be a patient representative or advocate, it is not necessary to have the condition yourself. It is more important that this person knows the needs of patients and what they encounter in their daily lives. It is also important that they know how to communicate this to stakeholders such as doctors, scientists, politicians and policy makers.

1.3 No patient organisation in your country

In case there is no national patient organisation, there is always an international patient organisation you can contact for advice/assistance. In addition, you can always organise a panel, focus group or patient expert group with your own patients in your hospital(s). You can always ask the known patients advocates to help.

2. Needed for your grant application

2.1 Letter of support

A letter of support from the patient organisation is often mandatory and if not, it is always a valuable contribution. A letter of support like 'we support this application' is not enough.

The letter must contain:

- that the project proposal has been discussed with the organisation concerned
- the idea and the implementation is feasible and valuable from a patient perspective.

Example: if every month a liver biopsy is needed, we expect that patients will drop out if the burden is too high and that affects the research or it will drastically affect the number of patients included. In general, we ask ourselves: what does the patient gain from this?

- that the idea definitely contributes to improving quality of life. (Note: Even basic laboratory research can make this contribution to quality of life)
- a short summary of the contributions that the patient organisation can make (see also 2.4)

2.2 Budget

Patient Participation is not for free! Patients or patient representatives, patient advocates give their effort and time. Even if the patient organisations is led by volunteers only. You don't pay the representatives in person, but the patient organisation.

But think also about a Focus group in your hospital: patients have travel costs and a cup of coffee or tea is the minimum you can offer them. But maybe you have to invite them to your physical meetings and want them to speak. Full reimbursement of travel cost and hotel costs etc. is required.

The budget for patient participation is always a difficult question. It depends on the contribution of the patient organisation. Discuss this with the patient organisation. Some countries (e.g. the Netherlands) have tariffs for patient participation.

2.3 Patient representative/advocate as member of the project team/advisor

Include a patient representative in your application as a member of the project team.

Not all grant-awarding institutions allow patients to serve on scientific committees. In that case, include them as advisors.

2.4 Suggestions of descriptions in applications chapter *involvement patients/patients representatives/patients organizations*

The patient organization/representative will:

- follow the decision-making processes and is supporting to ensure a democratic process of patient representation
- provide the perspective of patients on all relevant aspects in the policy & organisational processes
- promote and encourage, where possible a patient-centric approach in both delivery of clinical care, service improvement and strategic development & decision-making
- advocate for care that is patient-centred and respectful of patients' rights and choice
- provide the patient perspective on the application of personal data rules, compliance of information consent & management of complaints
- ensure that processes to address all ethical issues and concerns for patients are in place, balancing patient and clinical needs appropriately
- advise on transparency in quality of care, safety standards, clinical outcomes and treatment options
- monitor the performance of the results by reviewing quality indicators such as the clinical outcomes of diagnosis and treatment
- contribute to the development and dissemination of patient information, policy, good practice, care pathways and guidelines
- advice to a general project website with a lay version (in the native language of several partners)
- contribute to research e.g. defining research areas important to patients and their families and disseminating research-related information in a lay version by: regular articles in their quarterly magazine concerning relevant information about the project, on websites and other social media like Facebook and twitter
- share the information with their colleague patient organisations related to the subject
- inform their umbrella organizations by articles/reports, presentations during international meetings
- advise about providing a lay version of the final results of the project

3 Help/support needed

Don't hesitate to contact us! We patient representatives/advocates know each other very well and can always help you or send you to the right person.