

Survey on Patient and Public Involvement (PPI) in gynecologic oncology research

Thank you for accepting to participate in this survey

If you have already received this questionnaire and filled it out, we thank you for participating.

Gender ☐ Woman ☐ Man ☐ Other ☐ I prefer not to say	Year of birth / / / / /
Profession ☐ Medical Oncologist ☐ Surgical Oncologist ☐ Gynaecologic Oncologist ☐ Medical trainee ☐ Nurse ☐ Other	Primary position ☐ Department Director ☐ Medical Director ☐ Medical Doctor ☐ Research Nurse ☐ Other
Affiliation ☐ University ☐ Hospital/Research hospital ☐ Research Institute ☐ Other	Career stage ☐ Early-career (≤ 5 years) ☐ Mid-career (6–15 years) ☐ Established career (16+ years)
Percentage of time spent on research ☐ 0% ☐ 1%-25% ☐ 26%-50% ☐ >50%	Which collaborative group are you a member of? ☐ MaNGO ☐ MITO ☐ Both of them
What is your institution/entity?	

Have you ever heard the expression “public and patient involvement”, usually abbreviated with PPI?

YES..... / /
 NO / /

We acknowledge that there is no unique, universally agreed definition of PPI in health research.

By PPI we mean research being carried out **“with” or “by” members of the public** - patients, service users and/or carers, or patient representatives - **rather than “to,” “about” or “for”** them. PPI in research consists in active collaboration about prioritization of research topics, choice of the study design, planning, conducting the study and/or disseminating of research results. By PPI we do not mean the recruitment of participants for the study (trial, survey, focus groups or interviews), or the dissemination of study results to the patients or public.

In this survey we will refer to patient and public involvement in the research by meaning people with disease, caregivers and family members, patient representatives, service users, or people with no experience of illness.

PPI in cancer research is becoming more and more widespread in today’s research environment; what are your thoughts on this? (Select all that apply)

- ☐ PPI is morally/ethically the right thing to do
- ☐ Public - patients, service users and/or carers, or patient representatives - can’t contribute in a meaningful way
- ☐ PPI should be implemented in any research study
- ☐ PPI is not always necessary
- ☐ PPI increases the chances of research study success
- ☐ I am not convinced of the benefits of PPI
- ☐ Other (please specify) _____

Have you ever involved public (patients, service users and/or carers, or patient representatives) in your cancer research activity?

- ☐ Yes
- ☐ No [questions about PPI experience not shown]

Would you be interested in participating in a PPI training course?

- ☐ Yes
- ☐ No [question about useful training not shown]

If NO, please specify why.....

What do you perceive to be the potential BENEFITS of PPI on cancer research?
(Please select up to 3 items)

- ☐ Ensuring that research results are relevant to the public
- ☐ Maintaining the connection to the real world
- ☐ Improving the research design
- ☐ Improving patient recruitment
- ☐ Improving dissemination of results
- ☐ Improving knowledge and skills of the research team
- ☐ Obtaining new perspectives on a research topic
- ☐ No benefits
- ☐ Other (please specify) _____

What do you perceive to be the potential NEGATIVE EFFECTS of PPI on cancer research?
(Please select up to 3 items)

- ☐ Identification of problems not relevant for clinical research
- ☐ Involving subjects not representative of target patient population
- ☐ Subtracting time/resources/funding from other research activities
- ☐ Distrust of researchers/research in general
- ☐ Hampering study feasibility
- ☐ No negative effects
- ☐ Other (please specify) _____

What do you perceive to be the BARRIERS to PPI in cancer research?
(Please select up to 3 items)

- ☐ Patients not understanding the complexity the research topic
- ☐ Difficulty in translating scientific to lay language
- ☐ Lack of time/resources/funding
- ☐ Values/priorities/expectations conflicting among the stakeholders
- ☐ Not knowing how to involve representative patients/public
- ☐ Lack of patient and public knowledge of research methodology
- ☐ Other (please specify) _____

What is REQUIRED for an EFFECTIVE PPI implementation in cancer research?
(Please select up to 3 items)

- ☐ A way to measure PPI impact
- ☐ PPI dedicated resources (service/function/staff)
- ☐ Training for researchers on how to implement PPI
- ☐ Training for public and patients partners
- ☐ Methods, materials, information and guidelines for best PPI practice
- ☐ PPI endorsement and support by the Institution
- ☐ Financial resources (funds)
- ☐ Logistical support
- ☐ Other (please specify) _____

Which is the priority level of PPI in cancer research given by your institution?

- ☐ High
- ☐ Medium
- ☐ Low
- ☐ I do not know

If PPI was not a requirement of research funders, would you choose to involve patients in your research?

- ☐ Yes
- ☐ No
- ☐ I do not know

According to you, how important is it to offer payment for public and patient involved in PPI activities?

- ☐ Very Important
- ☐ Important
- ☐ Moderately Important
- ☐ Slightly Important
- ☐ Not Important

Are you aware of any PPI training initiatives aimed at/dedicated to patients or patient associations?

- ☐ Yes
- ☐ No

If YES, which ones?

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In the last five years, how often was PPI included in your current and past cancer research projects?

- ☐ Always
- ☐ Sometimes
- ☐ Rarely
- ☐ Never
- ☐ I do not know [if “never “ or “I do not know” the next question is not shown]

In the past 5 years, in how many times has PPI been implemented in your cancer research projects?

/__/_/

Please, describe your level of satisfaction in doing PPI in cancer research.

- ☐ Very satisfied
- ☐ Satisfied
- ☐ Neither satisfied nor dissatisfied
- ☐ Dissatisfied
- ☐ Very dissatisfied
- ☐ I do not know

Why was PPI included in your cancer research?

(Please select up to 3 items)

- ☐ It is required by funder(s)
- ☐ It is required by our institutional policy
- ☐ It is morally/ethically the right thing to do
- ☐ It results in better research
- ☐ To improve recruitment and retention of participants
- ☐ I do not know
- ☐ Other (please specify) _____

In which activities/phases of the research process have you involved patients and/or their carers, service users, or members of the public?

(Select all that apply)

- ☐ Establishing research priorities
- ☐ Protocol development (study design, measurements choice, outcome definition)
- ☐ Contributing to funding application
- ☐ Discussing research methods
- ☐ Contributing in writing/reviewing patients information sheets
- ☐ Undertaking the research (e.g. identifying or promoting study participation, collecting data....)
- ☐ Data analysis and/or interpretation of results
- ☐ Dissemination of findings
- ☐ Other (please specify) _____

Which kind of PPI participants were involved in your cancer projects?

(Select all that apply)

- ☐ Patients and/or potential patients
- ☐ Caregivers
- ☐ Family members
- ☐ Organisations representing patients' interests (e.g. advocacy organizations)
- ☐ Members of the public who are the targets of project
- ☐ Other (please specify) _____

What type of training and education have you received to implement PPI in your cancer research projects?**(Please select up to 3 items)**

- ☐ I have received no training or education
- ☐ I have received informal training (e.g., blogs, website reviews)
- ☐ I have received Institutional training (e.g., seminars, courses)
- ☐ One-on-one advice and training from a colleague with PPI experience
- ☐ One-on-one advice and training from a patient representative with PPI experience
- ☐ Other (please specify) _____

Which kind of training would be useful for you?**(Please select up to 3 items)**

- ☐ Case study discussion
- ☐ Practical tools and suggestions
- ☐ Theoretical bases
- ☐ Overview of methods available
- ☐ Collection of experiences
- ☐ Other (please specify) _____

Thank you for your collaboration