



PATIENT AND PUBLIC
INVOLVEMENT
IN RESEARCH





WHY PATIENT AND PUBLIC INVOLVEMENT IN RESEARCH?

The Danish Cancer Society is a patient organization and as such represents cancer patients' voice politically and experientially. The Danish Cancer Society has extended experience with involving patients and the public in a multitude of activities at different levels.

The Danish Cancer Society is a major funder of Danish cancer research and also houses intramural research at The Danish Cancer Society Research Center. There is a growing interest in and awareness of involving patients and the public in research with the purpose of improving the:

- Relevance and quality of the knowledge produced by research
- Appropriateness of the research procedures applied
- Democratic representation of patients and the public in research

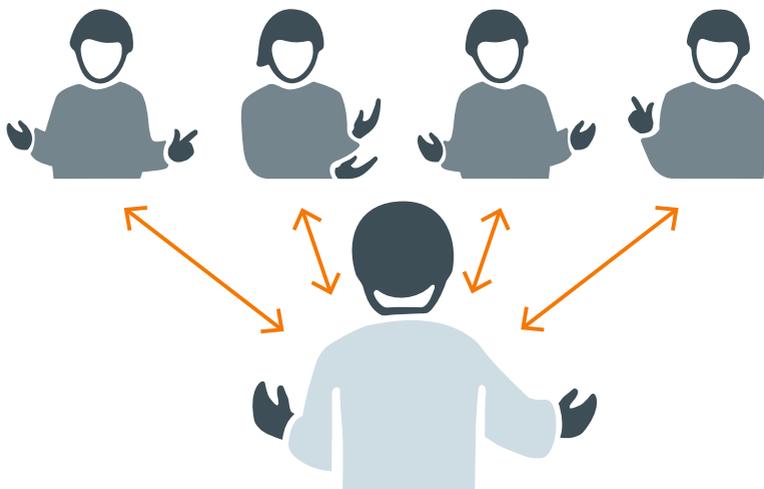
Active and relevant involvement of patients and the public in our research

is a prioritized area at the Danish Cancer Society Research Center and our researchers are expected to involve and engage patients and the public in line with current evidence.

This guide has been developed as a brief introduction for researchers working at the Danish Cancer Society Research Center who wish to involve patients and the public in their research process from e.g. basic in vivo and in vitro biological research, epidemiological registry-based studies of risk factors and clinical outcomes, to supportive care interventions.

How to get started?

This guide encourages self-reflection on how to apply patient and public involvement. The guide provides inspiration to involve patients and the public at different stages in the research process.



PATIENT AND PUBLIC INVOLVEMENT

Patient and Public Involvement at the Danish Cancer Society Research Center

We have established a Patient and Public Involvement in Research (PPI-R) Panel consisting of 7-10 cancer patients or relatives.

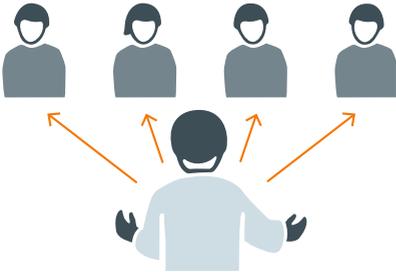
The aim of the panel is to encourage that the patient and public perspective is included in research in the Danish Cancer Society Research Center.

The panel meets twice per year. At the meetings, individual researchers will be able to get feedback on their specific research projects in writing or in person. Individual members of the panel can also be invited to solve specific tasks in an individual research project where their perspective can make a difference: e.g. by providing feedback on ethical questions, on recruitment procedures or on patient information materials.

For more information, contact
KBF-patient@cancer.dk

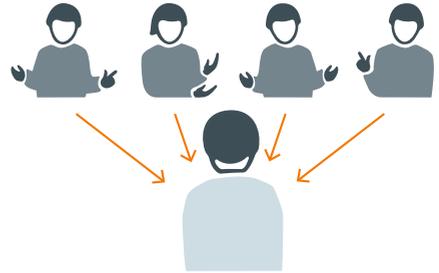
INFORM OR EDUCATE

Level 1



GATHER INFORMATION

Level 2



5 PRINCIPLES OF INVOLVEMENT

Five leading principles of patient and public involvement have been defined to ensure the best possible structure and outcome. These encompass that involvement should be:

- **Relevant**
Involve patients and the public in the relevant stage of the study
- **Respectful**
Apply high ethical standards, clarify expectations, make a contract or informed consent
- **Realistic**
Be realistic about what aspects patients and the public may contribute to
- **Research plan**
Make a plan for the involvement process and share this with the patient and the public
- **Responsive**
Give feedback to the patients and the public on how they have contributed to the process

Levels of involvement

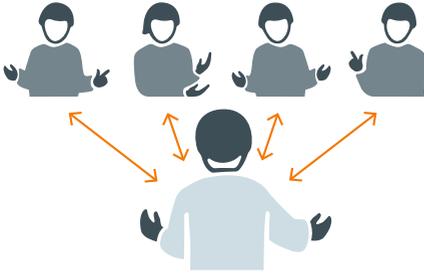
Patients can be involved at several different levels from informing patients about the research results to active engagement in project planning and execution to an advocacy role related to the research project's interests and outcomes.

The most appropriate level of involvement depends on the individual research project.

All research projects at the Danish Cancer Society Research Center should consider applying patient and public involvement, and if relevant, an appropriate level of involvement.

DISCUSS

Level 3



ENGAGE

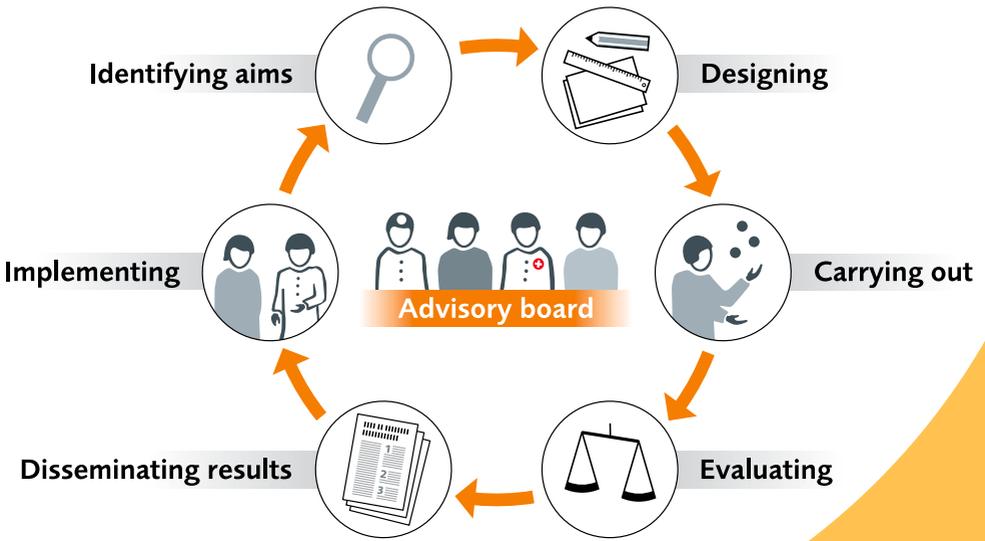
Level 4



PARTNER

Level 5





THE RESEARCH PROCESS

Stages of involvement

Depending on the individual research project, patients and the public can be involved in one or more of the following stages.

ers with an example of everyday life with a specific disease that may e.g. further underline the relevance of the proposed aims or perhaps add new research questions to the study.



Identifying aims

Prior to developing a research protocol, patients and the public can be asked to give feedback on:

- Relevance of the research theme
- Prioritizing aims within the research project
- Add new aspects of the research question that patients and the public identify as important.

Patients may provide the research-



Designing

During protocol development, patients and the public can be asked to:

- Identify areas that might have ethical implications
- Help ensure that the recruitment process is feasible
- Help develop written information in plain language
- Help ensure that the content of the intervention/treatment is relevant and feasible.



Carrying out

During study management, patients and the public can be asked to:

- Discuss reasons for low recruitment, drop out or poor fidelity
- If necessary, plan changes in the project to improve recruitment, adherence to the study plan, and to prevent drop out.



Evaluating

During evaluation and analyses, patients and the public can be asked to:

- Discuss the interpretation of the results from a patient/ the public perspective
- Evaluate the patient and public involvement process.



Disseminating results

Prior to dissemination of the results, patients and the public can be asked to:

- Tell their patient story and experience, which may be included in articles to illustrate the aim or perspectives of the research project.
- Help develop dissemination plans including e.g. gaining access to patient or public forums that researchers are not aware of
- Be involved in presenting at conferences, patient organizations, support groups and hospitals
- Be co-authors or give feedback on journal and newsletter articles, as well as layman's articles.

Involvement may be especially relevant in the phase of disseminating research results where patients with a lived experience with a specific disease can help communicate the concrete implications the results can have in everyday life.



Implementing

Prior to implementing results, patients and the public can be asked to:

- Help ensure that the implementation process is feasible
- Help develop written information in plain language
- Help ensure that the content of the intervention/treatment is relevant and feasible.



Advisory board

Throughout the research process, patients and the public can be asked to participate as a member of the study advisory board to:

- Provide a forum for discussion of experiences from patient and public involvement
- Give feedback on the overall study process
- Help ensure that decisions consider patients' and the public's interest
- Generate and develop ideas for the research area
- Serve as ambassadors for research at the Danish Cancer Society Research Center



WHO

The guide was developed with inspiration from the following:

- *Levels of Involvement* was adapted from Patterson Kirk Wallace, as cited in Health Canada's (2000) Policy Toolkit for Public Involvement in Decision-making, p. 12
- *The Research Process* was inspired by NIHR INVOLVE, Resources, Briefing note eight: Ways that people can be involved in the research cycle at www.INVO.org.uk
- *Planning your involvement* was adapted from Cancer Research UK, Patient involvement toolkit for researchers at www.cancer-researchuk.org

Contact

For more information, contact KBF-patient@cancer.dk



Kræftens Bekæmpelse

PLANNING YOUR **INVOLVEMENT**

This worksheet has been developed to help researchers plan their patient and public involvement activities.
Fill out the worksheet on your screen or print (page 9) it and fill it by hand.

1. What problem are you trying to solve?

6. What method(s) of involvement will you use?

2. How can insights from patients and the public help you solve this problem?

7. How will you recruit patients and the public?

3. What questions do you need to ask to gather this insight?

8. What information, training or support will they need?

4. At what stage/s of your research do you want to involve patients and the public?

9. How will you give feedback to them on how their insights influenced the project?

5. Who is your target audience? What experience or skills do they need?

10. How will you evaluate the patient and public involvement?