



Nederlandse Federatie van  
Kankerpatiëntenorganisaties



# Towards optimal patient involvement in guideline development groups

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# Setting the scene

- Common approach in the Netherlands: Inclusion of two patient representatives in guideline development group
- Reported challenges:
  - Contribution of patient representatives relatively small
  - Little systematic reflection on how to support patients representatives in guideline development groups

# Aim

- Gain insight in effective strategies to optimize patient involvement in guideline development groups (GDGs)
- Context:
  - Comprehensive Cancer Centre the Netherlands (IKNL)
  - Dutch Federation of Oncological Patient Organizations (NFK)



# Methodology

- Two patient research partners included in project team
- Exploratory desk study
- 23 retrospective interviews
  - Process facilitators
  - Chairmen
  - Patient representatives

# Methodology

- Monitoring and evaluation of four oncological guideline development processes
  - Prostate carcinoma
  - Hepatocellular carcinoma
  - Esophageal carcinoma
  - Thyroid carcinoma
- Observations during GDG meeting, organizing additional activities
  - Preparation meetings, reflection meetings, working sessions, focus groups

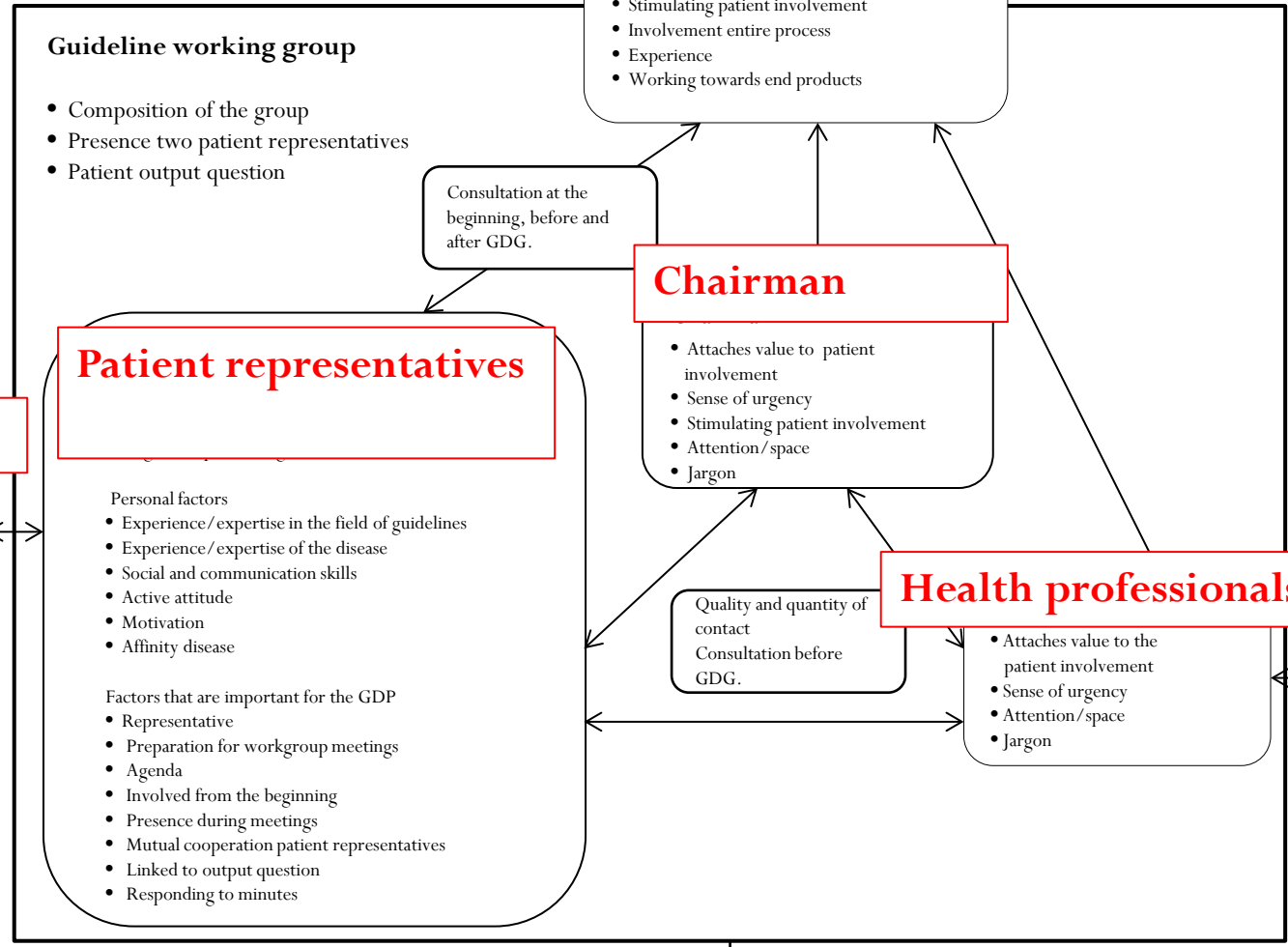
# Results

- Retrospective interviews and monitoring and evaluation of four oncological guideline development processes
- Development of factor analysis
  - Factors influencing patient involvement in GDGs
    - Strategies to optimize patient involvement

- Collaboration
- Training on guideline development for patient representatives
- Involve patient representatives at the start of the GDP

**Patient organizations**

- Quality criteria
- Select and support patient representatives
- Contact with patients
- Guideline development training



- Guideline**
- New / revision
  - Oncology / palliative
  - Volume and complexity of disease
  - Aim of the guideline, end products

IKNL

- Scientific organizations**
- Selection of professionals

# Patient representatives

- Moment of involvement in GDG
  - Include patient representatives at the start of the guideline development process
  - Include review question from patient perspective
- Knowledge of and experience with guideline development process
  - Provide guideline training to patient representatives



# Patient representatives

- Involvement in patient organization
- Contact with patient community
  - Include patient representatives who have access to, or contact with patient community
- Agenda
  - Stimulate patient representatives to formulate own agenda

# Process facilitator and patient organization

- Support patient representatives
  - Provide support through facilitation and organization of:
    - Preparation meetings
    - Reflection meetings
    - Focus groups
    - Working sessions

# Health professionals and chairman

- Attention and space
  - Specifically address and provide space for patient representatives during GDG meeting
- Express expectations and responsibilities
  - Organize start meeting with patient representatives and chairman

# Conclusions

- Supporting patient representatives is crucial
  - Responsibility of process facilitator and patient organization
- Participation activities optimize patient involvement
  - Preparation and reflection meetings
  - Consultative activities

# Conclusions

- Involving patient representatives at the start of the guideline development process optimizes patient involvement
- Inclusion of evidence based review question from patient perspective increases ownership, responsibility and motivation

# Discussion

- Many challenges are remaining:
  - Available resources to support patient representatives
  - Limited patient pool available
  - Professionalization of patients

**Thank you for your attention!**



# Disclosure of Interests (last 3 years)

Tirza de Lange -Tichelaar

I certify that, to the best of my knowledge, no aspect of my current personal or professional situation might reasonably be expected to affect significantly my views on the subject on which I am presenting, other than the following:

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