Patient participation in guideline development

Lessons for optimization: an action research approach

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Background

- Arguments for patient participation:
  - enhancement of legitimacy of decision making
  - increased quality and relevance of results
  - Normative ‘right’

- However, patient participation often requires additional resources and time

- Systematic reflections and scientific publications are limited

- Need to gain insight in methods and conditions in order to optimize patient participation
Project – overview

Project financed by ZonMW* (KKCZ programme)

Phase 1: Inventory study
- literature review (national and international)
- 39 interviews in the Netherlands
- 7 interviews internationally

Phase 2: Action research
- experiments in four guideline projects to optimize patient participation based on lessons learned

*The Netherlands Organisation for Health Research and Development
Project – phase 1

Findings phase 1:

- No consensus best practice
- Little attention for patient involvement in methodology of guideline development
- Difficult recruitment of certain populations
- Difficult for patients to have an equal voice in guideline development group
- Difficulties integrating patient input in guideline
- Little patient participation in revision of guidelines
- Need for evaluation of participation processes
Project – phase 2

4 guidelines:
- Recovery from gynecological surgery
- Diabetes and work
- Severe mental illness (SMI) and work
- Anxiety and depression (revision)

Selection criteria:
- Relevance relating to issues emerging from inventory study
- Diversity in health conditions
- Innovative methods of patient participation
# Evaluation framework

<table>
<thead>
<tr>
<th>Process criteria</th>
<th>Outcome criteria</th>
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<tbody>
<tr>
<td><strong>Stakeholder participation</strong></td>
<td><strong>Direct outcomes</strong></td>
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<tr>
<td>ratio patients/ professionals</td>
<td>consensus on guideline text</td>
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<tr>
<td>diversity en plurality</td>
<td>reflection of patient input</td>
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<td>adequate representation</td>
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<td><strong>Process structure</strong></td>
<td><strong>Translation guideline to practice</strong></td>
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<td>transparency of goals, roles, structure</td>
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<td>input of knowledge by experience</td>
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<td>active involvement patients</td>
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<td><strong>Process management</strong></td>
<td><strong>Indirect outcomes</strong></td>
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<tr>
<td>facilitation patient input</td>
<td>Enhancement of learning processes</td>
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<td>adapt process to patient</td>
<td>‘capacity building’ of patients/organisations</td>
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<td>support patient participation</td>
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<td>equal voice patients</td>
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Evaluation activities

In several cases:

- Guideline Development Group (GDG)
  - observation, interviews, reflection
- Focus groups
  - organization, facilitation, analysis, reporting

In specific cases:

- Development of website
- Delphi- study
- Case studies
Findings

- Preliminary findings of 4 cases
- Outcomes of interim evaluation; final evaluations to be done
- Data organised and presented according to evaluation framework
Findings – process criteria

**Stakeholder participation**

- No innovations in ratio professionals/patients
- Attention for diversity in patient population (mostly in focus groups)
  - However, definition of target population often unclear
  - Reaching special groups is difficult, but possible
- Attention for adequate representation of patients
  - Professional patient representatives in GDGs
Findings – process criteria

**Process structure**

- Goals, roles and structure mainly known to guideline coordinators
  - Clarification along the process
  - Input of patient representatives explicitly addressed
- Decision making in initial phase mainly outside of GDG
- Phases of involvement:
  - 2 cases: whole process
  - 2 cases: specific phases
Findings – process criteria

Proces management

- Support for patients not offered by management and not requested by patients, but if given it is appreciated and considered relevant
- Management supports patient participation
  - Not always a priority
- Patient representatives have equal voice in GDGs
  - Different for cases without patients in GDG
Findings – outcomes

*Expectations of participants*

- Difficulties in integration of patient preferences and guidelines
- Difficulties in representing special groups among patient population
- Implementation activities crucial for practical usability guideline
Points of discussion

- Recognizability of findings
- Generalizability of cases
- Bottlenecks and concerns:
  - Revision of guideline
  - Integration patient input with guideline
  - Limited influence on decision making in initial phase
Thank you!

Questions?

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