



Patient participation in guideline development

Lessons for optimization: an action research approach

Lia van der Ham, MS

Jacqueline Broerse, PhD

Saskia van Veen, MS

Maurits van Tulder, Prof. Dr.

Athena Institute, VU University Amsterdam

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

| <i>Process criteria</i> | | <i>Outcome criteria</i> | | |
|----------------------------------|---|-------------------------|-----------------------------------|--|
| Stakeholder participation | ratio patients/ professionals | Direct outcomes | consensus on guideline text | |
| | diversity en plurality | | reflection of patient input | |
| | adequate representation | | Translation guideline to practice | |
| Process structure | transparency of goals, roles, structure | | Indirect outcomes | Enhancement of learning processes |
| | input of knowledge by experience | | | 'capacity building' of patients/ organisations |
| | active involvement patients | | | |
| Process management | facilitation patient input | | | |
| | adapt process to patient | | | |
| | support patient participation | | | |
| | equal voice patients | | | |

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?



Contact information: lia.van.der.ham@falw.vu.nl

