

Patient Involvement

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Main questions

- what do we know about patient involvement in guideline development?
- how do patients evaluate their participation in the guideline development process?
- how could we implement patient involvement in guideline development?

Definition of patient perspective:

The patient is the centre of the medical universe,
around which all our work revolves and towards
which all our efforts tend.

J.B. Murphy (1857 – 1916)

Guidelines

systematically developed statements to assist **PRACTITIONER AND PATIENT DECISIONS** about appropriate healthcare decisions for specific clinical circumstances ¹

tools for making decisions in health care more rational, for improving the quality of health care delivery and for strengthening the **POSITION OF THE PATIENT** ²

1 Definition used in the AGREE Instrument

2 Definition used by the Council of Europe

Why patient involvement?

- patient is focal point of our health care
- it could improve quality of guidelines
- it could improve guideline implementation

Two studies

Dutch College of General Practitioners (NHG) and Dutch Association of Nurses and Careworkers (AVVV)

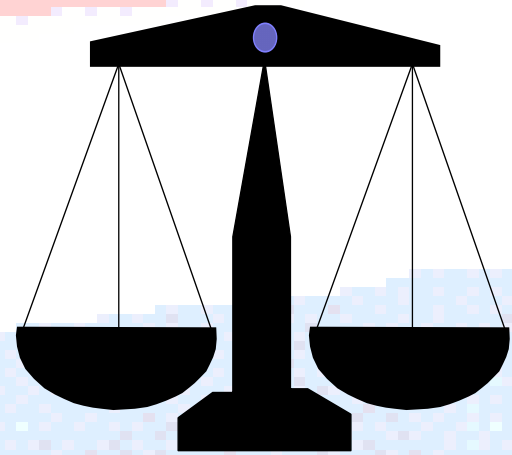
- both: literature study on methods used by guideline developers (1)
- AVVV: Delphi-study on how to involve patients in guideline development (2)
- NHG: Using patient focus groups (3)

Already existing methods (1)

- patient(s) participate in a guideline development group
 - patient representative
 - patient focus groups
 - literature study on patients unique preferences, concerns and expectations
- ⇒ best method?

Problems with all methods (1)

- representation of patients
- experience versus evidence



Results of the Delphi-study (2)

- patient has to know the patient perspective and must have expertise
- use the existing framework of patient association
- test guideline if patients perspective is incorporated in a good way → set up criteria for testing guidelines on patient perspective

Patient focus groups (3a)

- useful method to get in-depth information
- 5-10 patients and a chairman
- we gave no information in advance
- pilot with 4 guidelines:
 - low back pain
 - eczema
 - reumatoid arthritis
 - psoriasis

Patient focus groups (3b)

some statements of patients

- let the doctor say: “Eczema is not infectious”
- “after the diagnosis (R.A.), my whole world had collapsed”
- let the doctor ask: “What can I do for you?”

Conclusions focus groups (3c)

patients want:

- quick diagnosis and clear follow-up
- same advice from different people
- documentation and other information like addresses of patient organisations

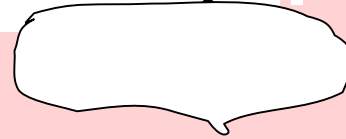
not (yet) in guideline:

- information about complementary therapies
- special attention for psycho-social effects

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Patient participation in guideline development group: patient opinion



Private clinic

- aim of the study:
how do patients (or representatives) evaluate their participation in guideline development?
- interim results of 19 questionnaires (47 send)
- 19 people from 13 different guidelines
- patients 3/19; representatives 7/19; both 9/19

Differences in professional vs. patient perspective

- patients have a more holistic approach
- patients plea for explicit recommendations
- patients ask for attention for psychosocial issues, information, etc
- patients focus is on individual, professional focus is on group



I had little or no influence on:

- finances
- group composition
- carrying out literature search
- measuring effects of guideline

I had some influence on:

- defining key questions for guideline
- search questions for literature search
- selection literature and review of literature
- writing text
- implementation of guideline
- developing information for patients

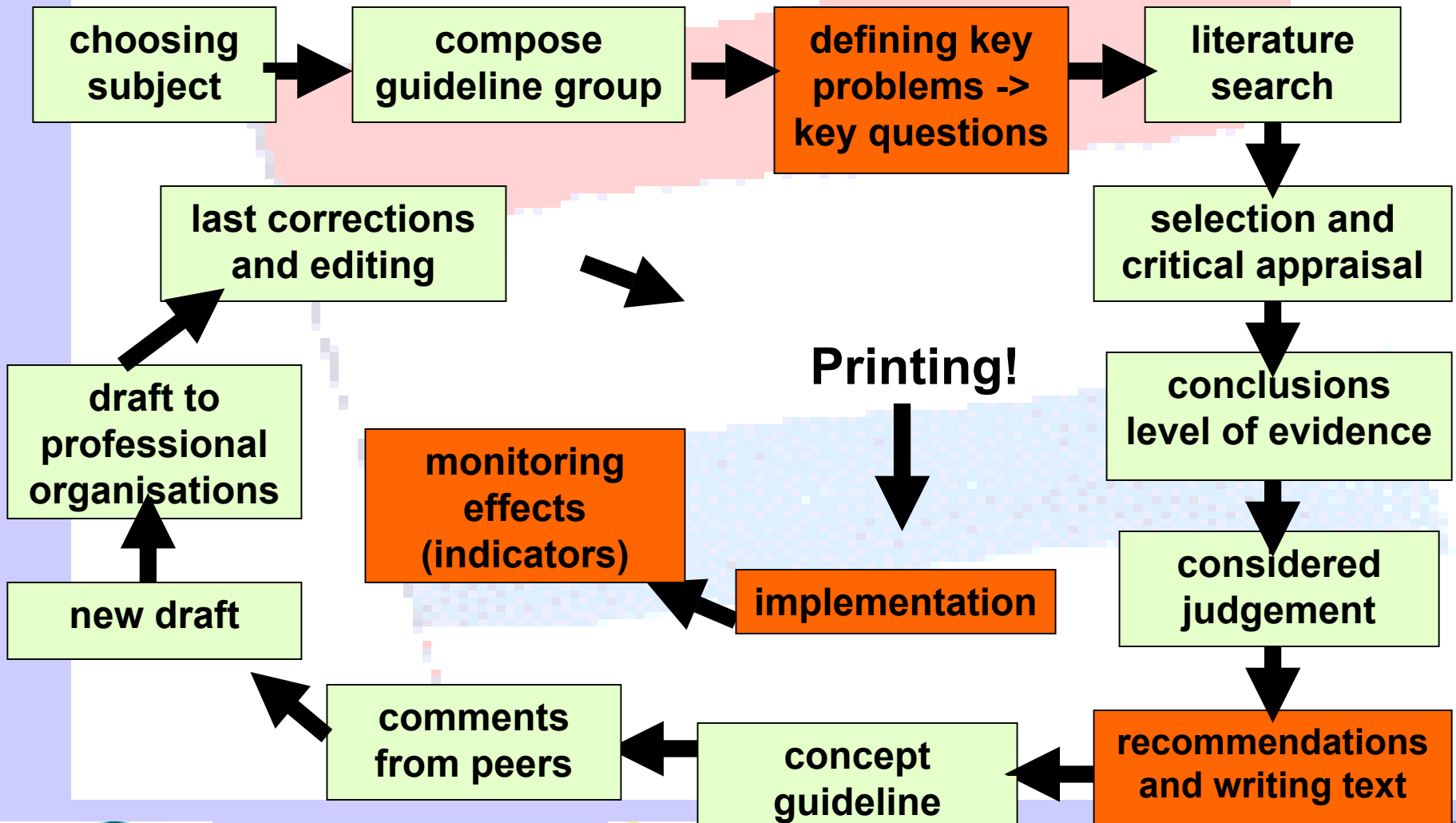
I had substantial influence on:

- defining key problems for guideline
- writing recommendations
- comment on (concept)text guideline

I would really appreciate it if these suggestions could be taken into account



I would like to have had more influence on:



Main questions

- what do we know about patient involvement in guideline development?
- how do patients evaluate their participation in the guideline development process?
- what can we learn and how could we implement patient involvement in guideline development?

What we have learned and how to implement this knowledge (1)

- participation of patients is advised, because it could result in:
 - (1) higher relevance of the key questions for patients.
 - (2) more attention for disease related subjects.
 - (3) better considered judgement of the evidence.
 - (4) better implementation of the guideline and higher compliance of patients

What we have learned and how to implement this knowledge (2)

- involve patients from (before) the start:
 - ask 2 or more patients in a guideline group, look also for patient-representatives
 - select a supportive chair in guideline group
 - be clear on expectations
- focus groups gives a lot of information
- have a mentor/coach available

What we have learned and how to implement this knowledge (3)

- develop supporting materials (eg. how to consult with fellow patients; how to get key problems)
- we need thorough evaluation of the effects of involving patients and which strategy is most successful in which situation
- do not re invent the wheel again;
Work together !

How to work together?

- the Dutch Patient Federation (NPCF) and several guideline development- and professional institutes will start a project to investigate the best method of patient participation in guideline development
- work together: start ~~national!~~ **International!**
- but also international cooperation has started (SIGN, Netherlands, NICE, Germany, Iceland, etc);
how can we take this further and how should GIN support this?

Interesting organisations / sites

Patient's perspective

- “Institute for Family-centered Care”, Washington USA:
www.familycenteredcare.org
- International Alliance of Patients' Organizations:
<http://www.patientsorganizations.org/>
- Cochrane consumer network: <http://www.cochraneconsumer.com/>
- Information published by the National Institutes of Health covering the topics of cancer, eye and ear, aging, heart, lung, blood disorders, alcohol and drug, and mental health:
<http://www.nih.gov/health/consumer/conicd.htm>
- Consumers can find clinical practice guidelines which are listed by condition, and published in plain-English terms:
<http://www.ahcpr.gov/consumer/>

Closing remarks from patients

- “working with professionals in a guideline group is an effective means of improving care together”
- “we learned a lot from participation; we now use elements of your methodology in some of our activities”