



Patient Involvement in Germany – How and when?

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- patient involvement – why?
- guideline development in Germany
- methods
- results
- conclusions



- patient involvement in CPG assures and improves quality of health care.
- patient involvement is an important tool for guideline implementation.





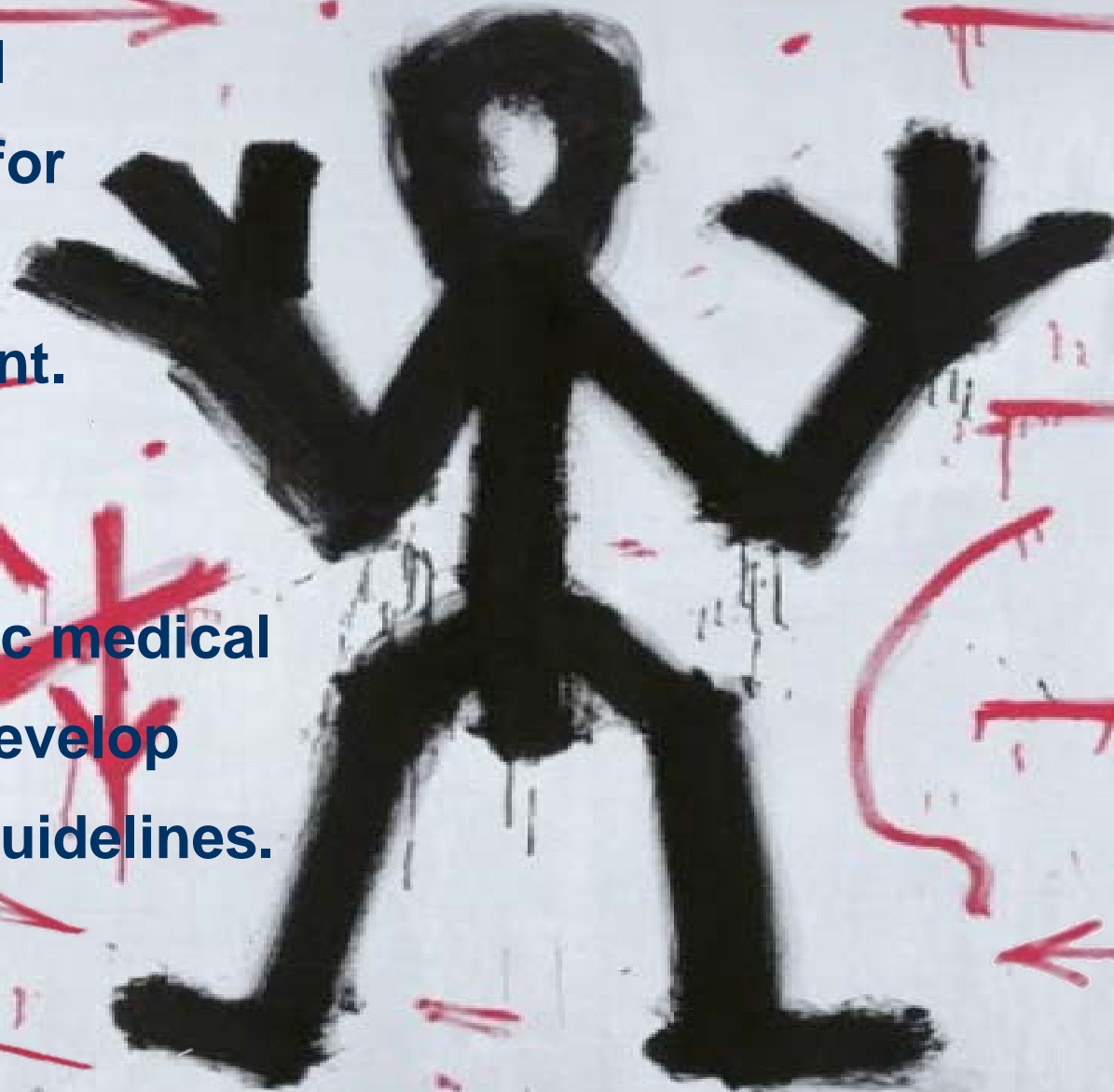
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Guideline Development in Germany



**No national
institution for
guideline
development.**

**All scientific medical
societies develop
their own guidelines.**



Guideline Development in Germany





**guidelines registred and classified
by the AWMF**

National Guidelines Programs:

- **National Disease Management
Guidelines Program**
- **German Guideline Program in
Oncology**





classification of guidelines according to AWMF

S1	<p>no systematic literature search</p> <p>no formal consensus process</p>
S2	<p>systematic literature search</p> <p><i>or</i></p> <p>formal consensus process</p>
S3	<p>systematic literature search and assessment of the evidence</p> <p>strength of guideline recommendation according to the level of evidence</p> <p>formal consensus process</p>



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Arbeitsgemeinschaft
der Wissenschaftlichen
Medizinischen Fachgesellschaften



Ärztliches Zentrum
für Qualität
in der Medizin

Deutsches Instrument zur methodischen Leitlinien-Bewertung (DELBI)

„German Instrument
for Methodological
Guideline Appraisal“

- the actual evidence-based guidelines (S2 and 3) have been assessed according to DELBI
- the guidelines have been assessed independently by two experts
- different results have been discussed
- the two experts have agreed about the final results



Domain 2, Question 5

„Patients‘ views and preferences have been sought“

strongly disagree

1	2	3	4
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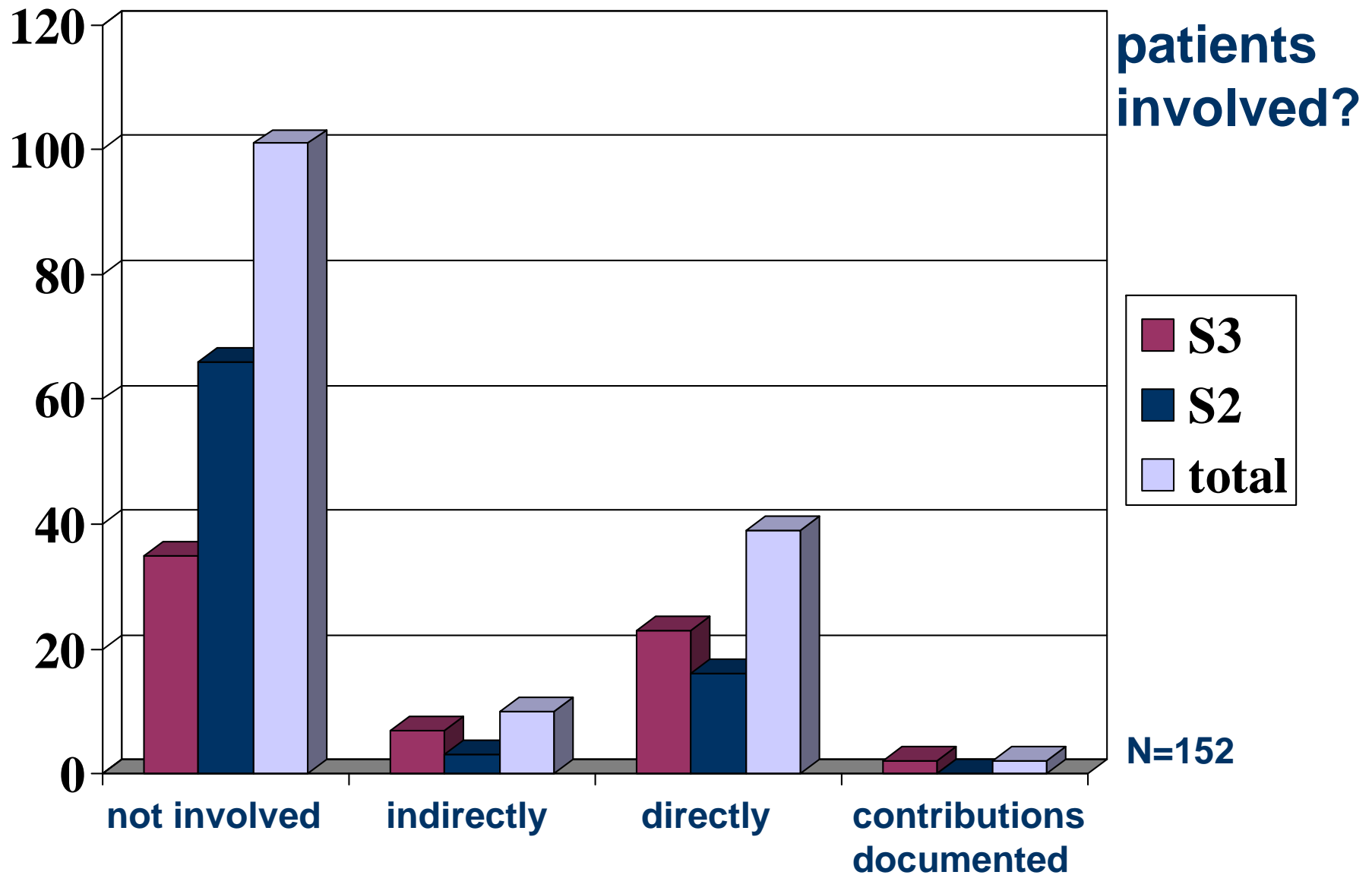
strongly agree

- 1 - patients are **not involved** or involvement has not been documented
- 2 - patients have been **involved indirectly** (i.e. by a review or public discussion)
- 3 - patients have been **involved directly** as members of the guideline development group
- 4 - decisional implications of patient involvement have been **documented**



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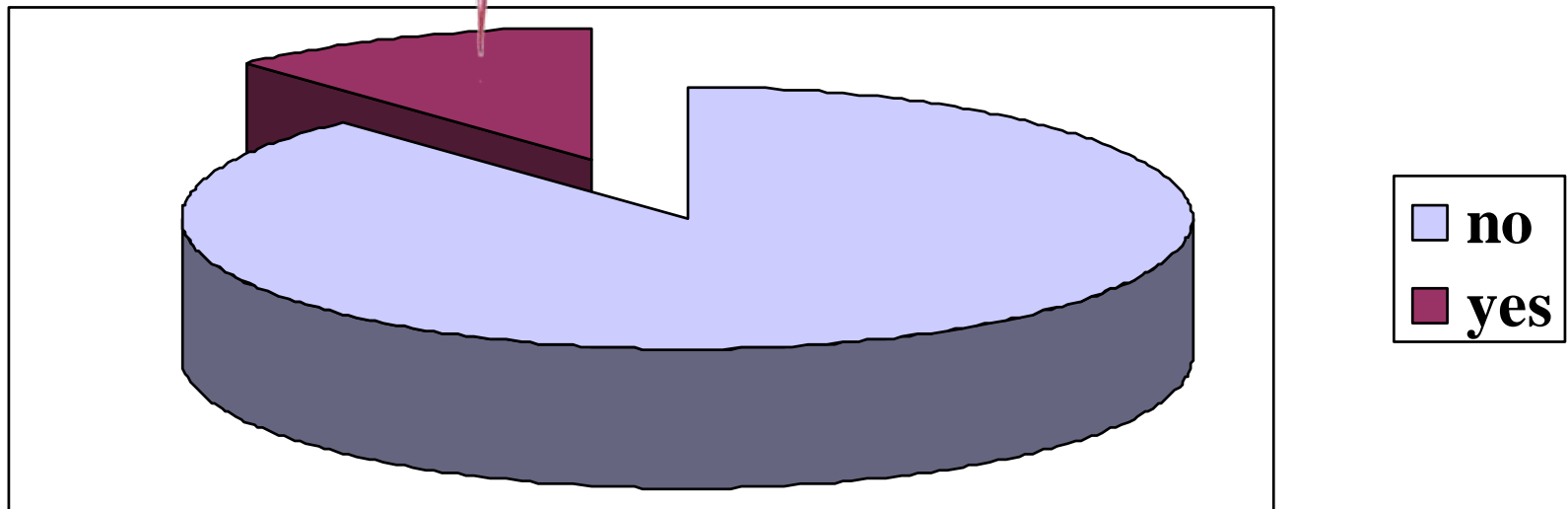
Results I





a methodology of patient involvement?

6 guidelines with a defined methodology of patient involvement being part of German National Guideline Programs



N = 51



- patients were involved in guideline development in less than 35%.
- in less than 5%, patient involvement followed a defined methodology
- the guidelines having a defined methodology of patient involvement were part of National Guideline Programs



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- Being an important implementation tool, patient involvement should become a standard in guideline development.
- Especially in terms of transparency in nomination of patient representatives and funding, patient involvement should be based upon a defined methodology.
- A defined methodology of patient involvement was found only within National Programs. Adaptation of this methodology by other guideline developers may enhance patient involvement in Germany.

