



Patient Guidelines in Oncology

A comparison of international standards and methodologies

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BACKGROUND

OBJECTIVE

METHODS

RESULTS

CONCLUSION

German Guideline Program in Oncology (GGPO)

LAUNCHED 2008

COOPERATION

Association of the Scientific Medical Societies

German Cancer Society

German Cancer Aid



German Guideline Program in Oncology (GGPO)

OBJECTIVES

Promotion of CPG development

Prioritization of topics

Improvement of implementation and evaluation

- **Patient guidelines**

- Short / Long versions of CPGs

- Quality indicators (linked to registries)

Independent funding



Patient Guideline Development Process

Agreement on the PG structure (editorial staff)

Translation of recommendations of the CPG (moderator)

Developing and writing of the PG (editorial staff)

Public / Peer review

Final editing

Publication

Controlling quality standards

modification

transfer of evidence-based recommendations from clinical guidelines

peer review by experts of the clinical guidelines

patient participation

provision of formal demands for good patient information

transparency in conflicts of interest



three-month phase of consultation with a structured feedback system

quality assessment after publication by an external institution following the quality criteria of the DISCERN instrument

results considered in reissue

Patient Guideline?


GGPO's view of "Patient Guidelines"

Patient guidelines are providing information about cancer in order to enable an informed decision making of patients.

They offer patients the opportunity to address relevant questions a part from the clinical aspects of disease and to bring in own experiences

Key element:

→ Translation of the evidence based recommendations of a current CPG into an understandable language for consumers



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Objective

Assessment of the inventory of oncological patient guidelines within G-I-N member organisations

Comparison of patient guideline development



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Screening process

Screen Homepages all G-I-N current and former members

- By search functions using terms:
 - „patient information“ „patient guideline“ „lay version“, „consumer resources“
- By hand

Check documents

- Oncological topic
 - PG linked to CPGs? Translation of Recommendations?
 - Methodology described?
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Results

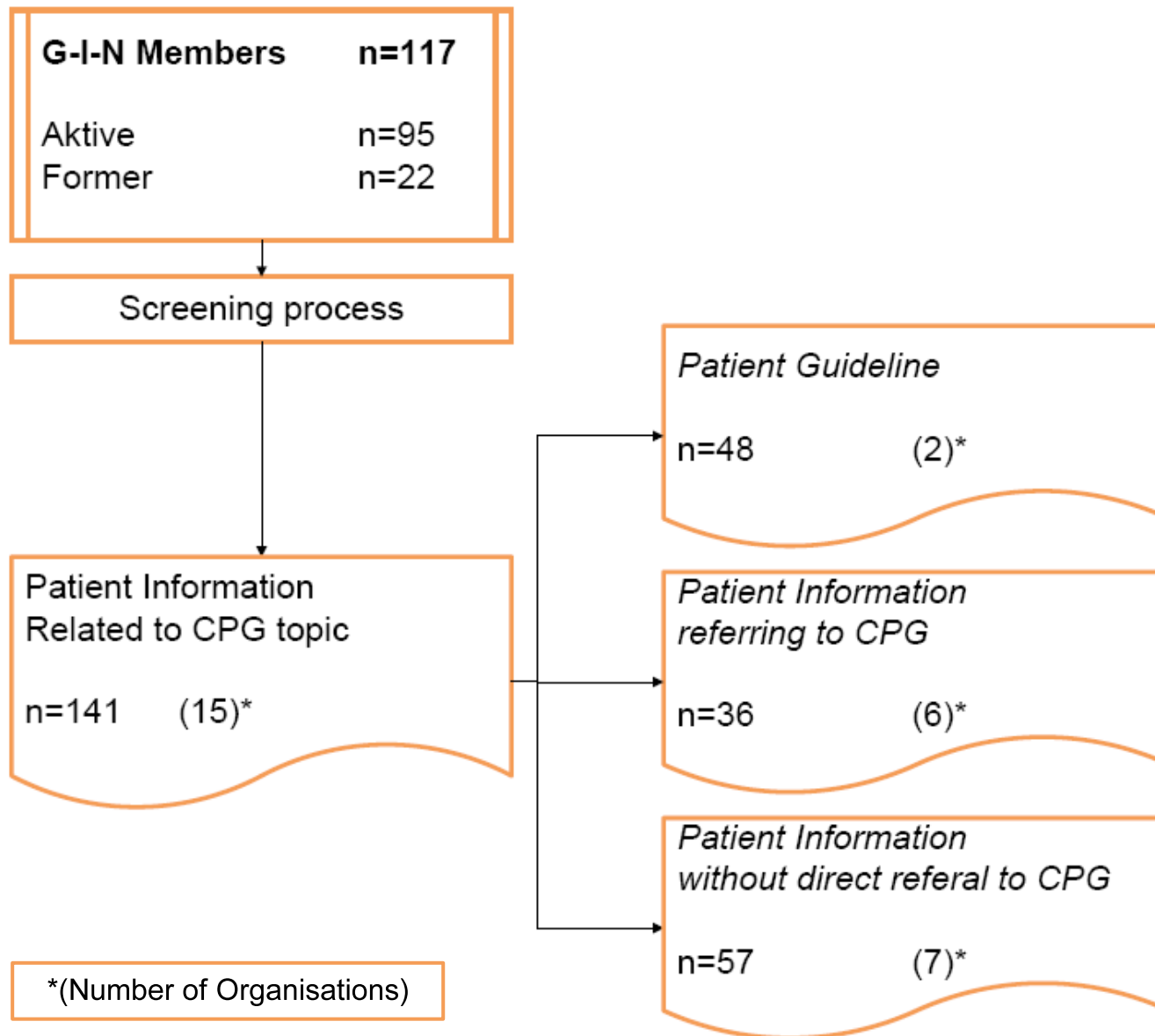
Search performed on February/March 2010

G-I-N Members (current and former) n=117

Available Homepages n=113

Included by language E,G,D,F n=99

Homepages with PI (Oncology) n= 15



Patient Guideline

n=48 (2)*

NICE

GGPO (ASMS, GCS)

Patient Information referring to CPG

n=36 (6)*

ACCC

ACP

ASCO

FNCLCC

SIGN

NZGG


Patient Information without direct referral to CPG

n=57 (7)*

AUA, NBOCC et al.

Limitations

Search performed on the world wide web:

- > missing of relevant data
documents not found on the homepage
 - > search is fairly reproducible
 - > language restriction
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Patient Guidelines in Oncology

Patient Guidelines pose an important tool for guideline implementation by translating recommendations and background information of the CPG into an understandable language and enabling patients to share medical knowledge in order to make decisions on the best available evidence

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Conclusions

Some G-I-N members are offering Patient Information on Cancer topics


Quality and format of this information is quite inhomogeneous

Methodology is generally not reported (and therefore incomparable)

Development of Patient Guidelines (PG) translating current CPGs are uncommon among G-I-N members



Implications

- Methodology of development of PI should be reported
 - The need of PG in general and explicit translation of the recommendations of a CPG should be discussed
 - A methodology of PG development could be a topic of interest within the G-I-N Community
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Thank you!

