

Patient questionnaires: Standards and requirements



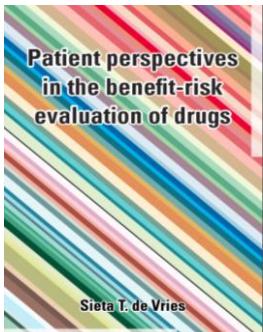
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Background

- Social psychology
- UMCG
- Department of Clinical Pharmacy and Pharmacology
- Research interests
 - Patient perspectives/experiences
 - Risk communication
 - Personalized drug treatment (e.g. gender differences)
 - Psychological aspects drug therapy



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Why asking patients directly?

*In the end, it is all about the patient.
The patient is the one with treatment
preferences, the one with specific
(medication) beliefs, the one who is
taking a drug as prescribed or not, the
one experiencing side-effects, and so on.*



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How to do that?

1. Define the construct to be measured
2. Select the measurement method
3. Select and formulate items
4. Answer options + Scoring issues
5. Pilot-testing



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1. Define the construct to be measured

- What do we want to measure? Why?

Efficacy

Safety

Attitudes

Which persons
use these
medicines

Complementary/
Alternative
medicine

Number of
users

Type of
medicines used

Expenditures

Use over time

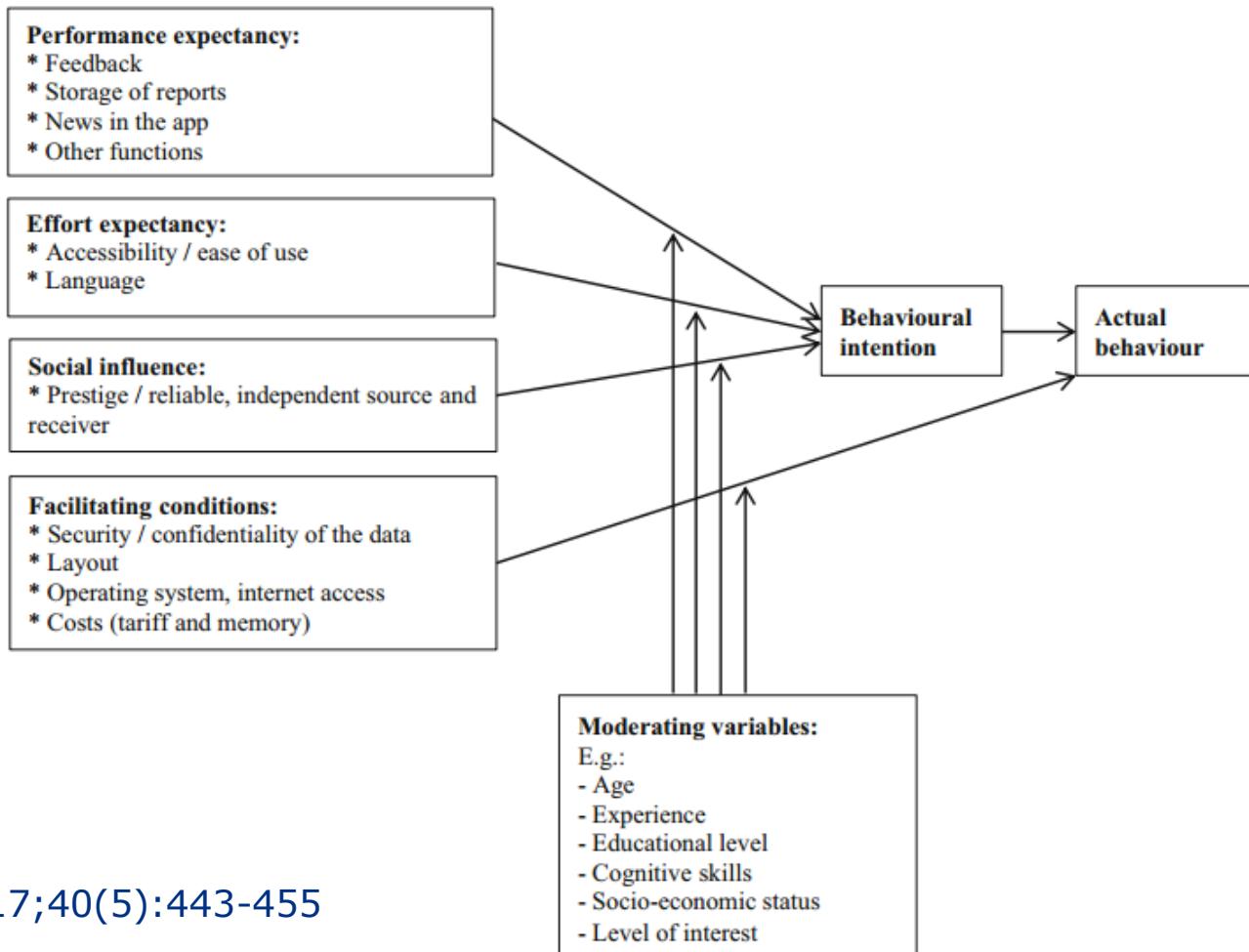
Effects of an
intervention



1. Define the construct to be measured

- What do we want to measure?

- Theoretical model
- Expert opinion
- Literature review
- Qualitative study



1. Define the construct to be measured

- What is the target population?

Examples

- Children? Adults? Elderly?
- Diseases?
 - People with dementia
 - Measurement of physical functioning



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2. Select the measurement method

- Methods should match construct to be measured
- Questionnaire vs interview
 - Costs + time
 - Self-explanatory vs option to explain
- Single item vs multi-item
- Online vs paper-based



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How to do that?

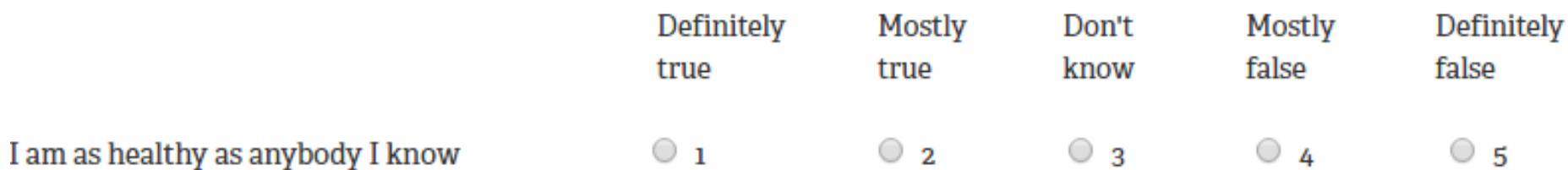
1. Define the construct to be measured
2. Select the measurement method
3. **Select and formulate items**
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3. Select and formulate items

- Perform literature search
 - Helps generating ideas
 - Saves time and effort
 - Ability to compare results across studies
 - Critical evaluate existing questions
 - Different language



- Development in collaboration with experts
(e.g. clinicians, patients)

Practical tips

- Avoid difficult words, complex sentences
- Be specific
 - Young adults would be more likely to use CAM if there were more CAM clinics
- Ask one question in an individual item
 - Young adults believe that CAM builds up the body's own defences and promotes self-healing
- Negative wording should be avoided
 - e.g. I do not take alternative medicines
- Draft many questions in the draft stage but do not include too many in the final questionnaire
- Response options should match with the questions and all options should be provided



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Type of questions

- Open-ended questions
 - In case of a large number of possible answers
 - Not all answer options known
 - Importance of capturing all details
- Closed-ended questions
- Mixed questions

25. Have you obtained any particular benefit from the CAM you used?

(A) Yes (specify) -----

(B) No

26. Did you experience any unwanted effect from the CAM you used in this cancer?

(A) Yes (specify) -----

(B) No

Examples open-ended questions

29. Can you describe the side effect in your own words?

32. How often did you experience this side effect during the past 4 weeks (on how many or which days)?



Examples of closed-ended questions

- Binary options

15. Have you used any thing other than that given to you by a medical doctor to treat this cancer.

(A) Yes

(B) No

- Mutually exclusive response options

2. What is your gender?

Male

Female

Other/prefer not to say

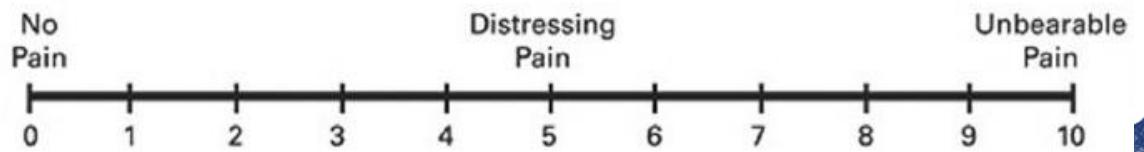
- Multiple response options

23. What are your reasons for deciding to use CAM (you can choose more than one)

- (A). You were disappointed that conventional treatment is not working
- (B). Conventional treatment is too toxic or too mutilating
- (C). You think CAM is more in keeping with your beliefs and your inner self
- (D). you want to take control of your treatment and your faith in your own hands
- (E). Conventional treatment is too mechanistic/technological and lacks human touch
- (F) You are just trying every thing that can help
- (G) Others (specify plse)

- Visual Analogue scale

Choose a Number from 0 to 10 That Best Describes Your Pain



Analytical methods

- Qualitative analyses
- Quantitative analyses
 - Categorical
 - Nominal: Number of classes that lack an order
 - Ordinal: Number of classes that have an order



- Continuous:
 - Interval: Scores expressed in numbers for quantification
 - Ratio: Absolute (true) zero point



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5. Pilot-testing

- Test in a small sample of people
 - Feasible
 - Comprehensive
 - Relevance
 - Completeness
- Adapt
- More rounds of testing may be useful



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What else

- Recruitment strategies
 - Population & timing
 - Incentives?
- Representativeness:
How well the sample compares with the population of interest
- Response rate:
Number of returned questionnaires / total sample who were sent the questionnaire
- Ethical approval to conduct study



Conclusion

- Time and effort are needed
 - Research questions need to be clearly defined
 - Development of survey should be done carefully
 - Keep language simple
 - Test before use



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References

Books:

- Drug utilization research: Methods and Applications
- Measurement in Medicine: A practical guide
- Health measurement scales: A practical guide to their development and use
- Improving survey methods: Lessons from recent research

Papers:

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