

# Patient questionnaires: Standards and requirements



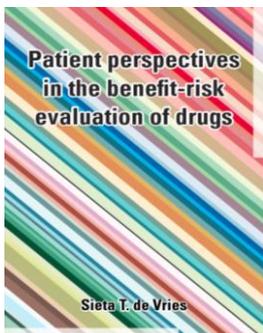
Sieta T. de Vries  
Post-doctoral researcher



University Medical Center Groningen

# 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



# 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.*



# 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



# How to do that?

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



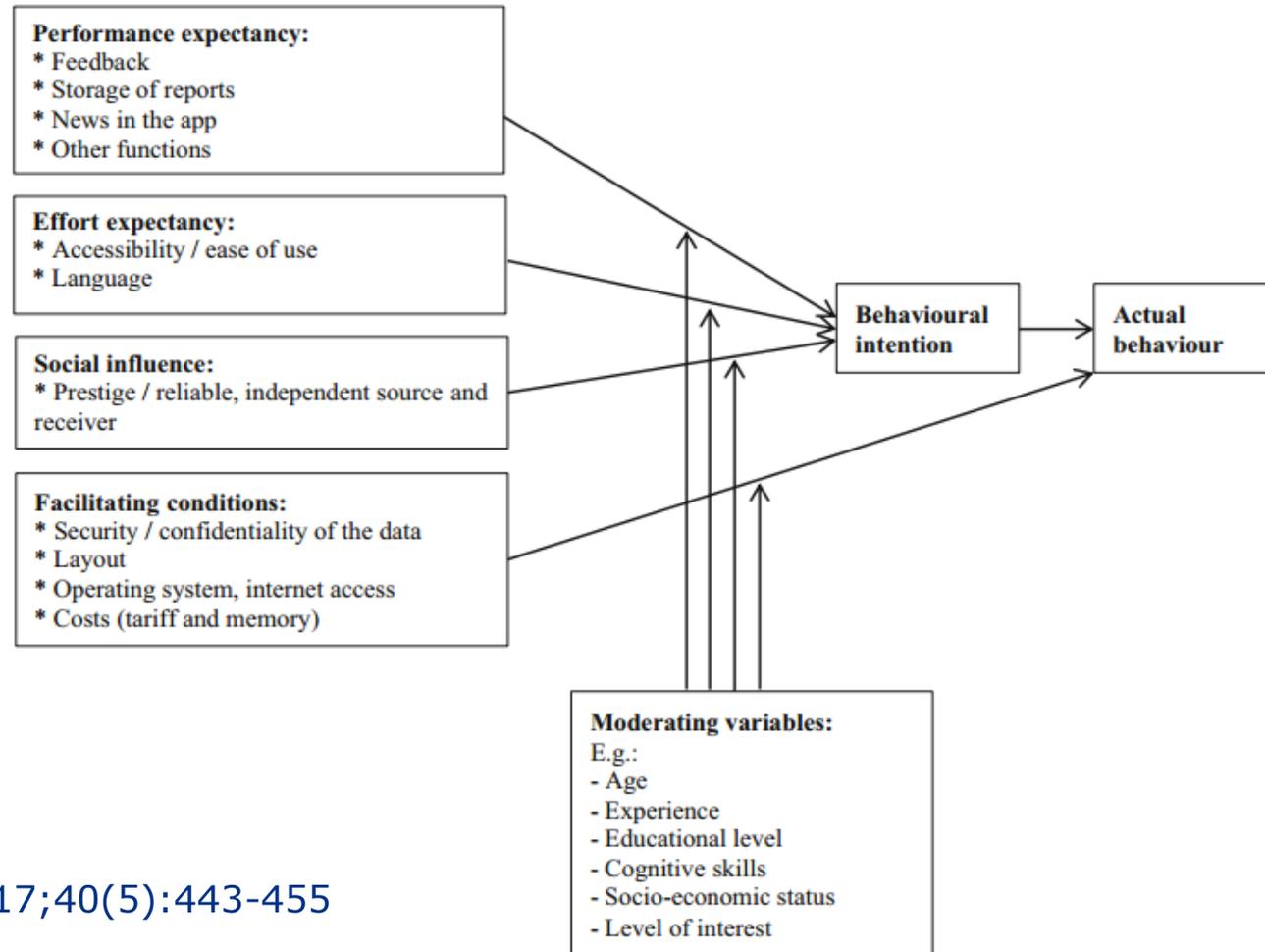
# 1. Define the construct to be measured

- What do we want to measure? Why?



# 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



# How to do that?

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



## 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



# 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



### 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

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
I am as healthy as anybody I know	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5

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



# Practical tips

- Avoid difficult words, complex sentences
- Be specific
- Ask one question in an individual item
- 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

Young adults would be more likely to use CAM if there were more CAM clinics

Young adults believe that CAM builds up the body's own defences and promotes self-healing



University Medical Center Groningen

# 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



# 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)?

.....





# 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



# 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



## 5. Pilot-testing

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



# 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



## Follow-up Plan

- ~~Send invitation~~
- ~~1st Reminder~~
- ~~2nd Reminder~~
- ~~1st Call~~
- ~~2nd Call~~
- Send silly cartoon
- Beg
- Hire goons
- Release hounds

# 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



# 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:

- **Hyland et al.** Developing a measure of attitudes: The holistic complementary and alternative medicine questionnaire. Complement Ther Med 2003.
- **Patterson et al.** A CAM questionnaire for young adults. Integr Med Insights. 2009.
- **Ezeome et al.** Use of CAM by cancer patients at the university of Nigeria teaching hospital, Enugu, Nigeria. BMC Complement Altern Med 2007.
- **Draugalis et al.** Best practices for survey research reports: A synopsis for authors and reviewers. Am J Pharm Educ 2008.
- **De Vries et al.** Factors influencing the use of a mobile app for reporting ADRs and receiving safety information: A qualitative study. Drug Safety 2017.
- **De Vries et al.** Development and initial validation of a patient-reported adverse drug event questionnaire. Drug Safety 2013



[www.umcg.nl](http://www.umcg.nl)

[s.t.de.vries@umcg.nl](mailto:s.t.de.vries@umcg.nl)



University Medical Center Groningen