

**KU LEUVEN**

# VALUE AND APPLICATION OF QUALITATIVE RESEARCH IN PATIENT PREFERENCE STUDIES

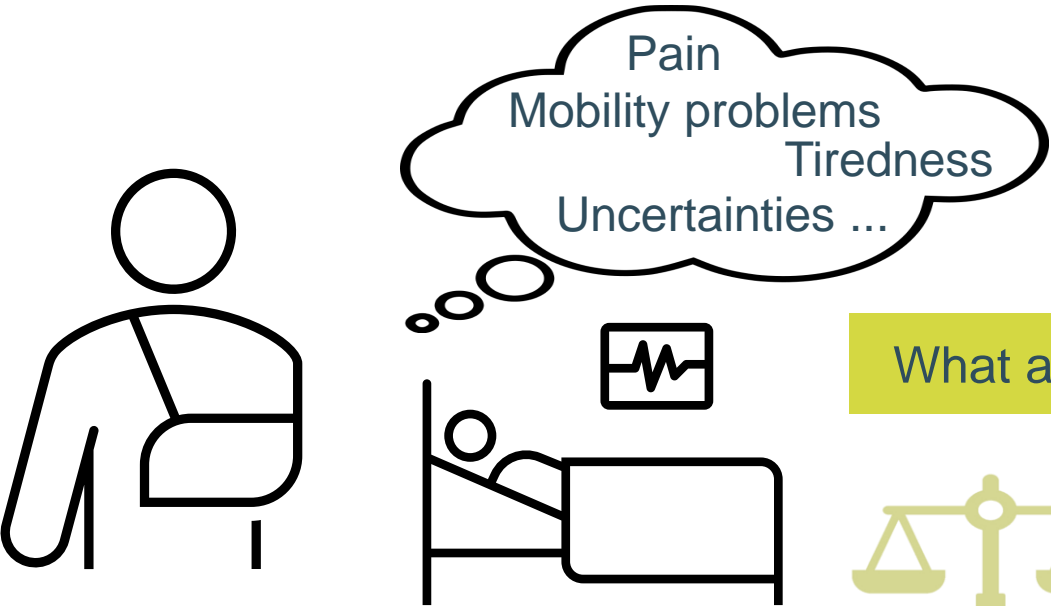
## Case studies in Multiple Myeloma, Duchenne and Inflammatory Bowel Disease

Dr. Rosanne Janssens  
RSNN meeting Utrecht  
5-09-2022



# Why qualitative research on patient preferences?

→ To obtain in-depth insights into **what matters to patients & why:**



What are unmet needs according to patients?

What are treatment outcomes that patients want from treatments?

What are trade-offs that patients are (un-)willing to make?

What are side-effects that patients (do not) find acceptable?

What are uncertainties that patients (are not) willing to take?

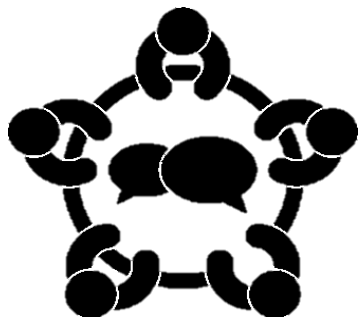
How do different disease and treatment effects impact patients' quality of life?

# Why qualitative research on patient preferences?

→ To inform **attributes and levels** of subsequent preference survey

## Qualitative study

## Quantitative study



EU Clinical Trials Register

ClinicalTrials.gov

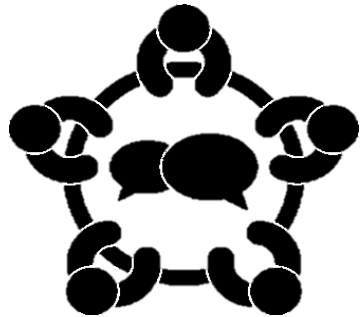
Interviews vs focus group discussions?  
 Online vs face to face?  
 Length and understandability of questions?

	A. Therapy A	B. Therapy B
Type of therapy	Corticosteroids	Gene therapy
Effect on life expectancy	12 years	14 years
Risk of life-threatening side effects related to the therapy	5% (5 out of 100 patients)	10% (10 out of 100 patients)
Years that ventilatory support is postponed	4 years	7 years
The number of years that you to maintain your current physical functional status	3 years	4 years
Years and number of patients in which that therapy has been studied	48 years; 20,000 patients	10 years; 100 patients

Please indicate your preferred choice:

Therapy A       Therapy B

# Attributes should be...



**Meaningful & relevant  
from the patient's  
perspective**

**Inclusive of all aspects  
that might be important  
participants' decisions**  
>< ignoring important  
attributes may bias  
findings

**Plausible**  
(related to existing or  
potential  
treatments/disease  
effects)



**Clear**

**Understandable**

**Not significantly  
overlapping with another  
attribute**

# How did qualitative research make a difference?

1. Ensured inclusion of **PATIENT** relevant attributes; inclusive of all aspects important to patient decision-making

*“For me fatigue is something I could not accept as a side-effect.”*

Inflammatory Bowel Disease

Decreased libido

Fatigue

Frequency of having to go to the toilet

Risk of undergoing surgery

...

Multiple Myeloma

Additional life expectancy in years

Risk of life-threatening side effects

Mobility problems

...

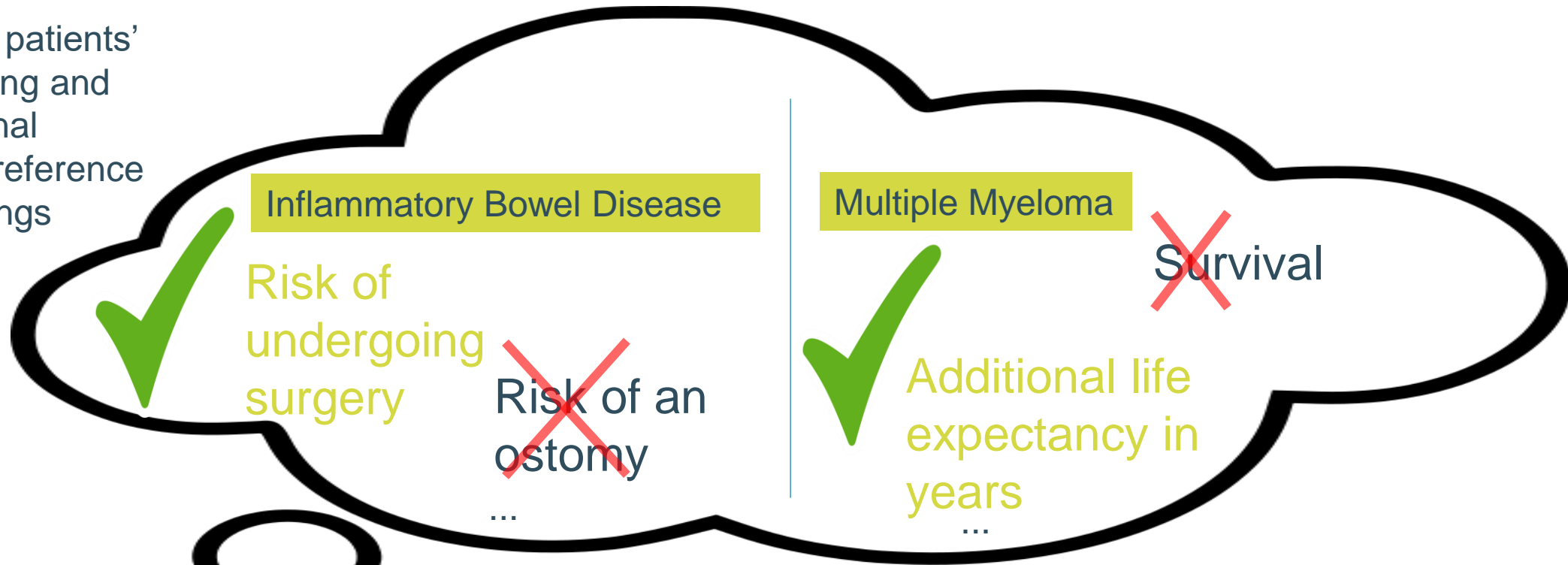
*“If something were found that would improve the whole tingling sensation that has become chronic.”*



# How did qualitative research make a difference?

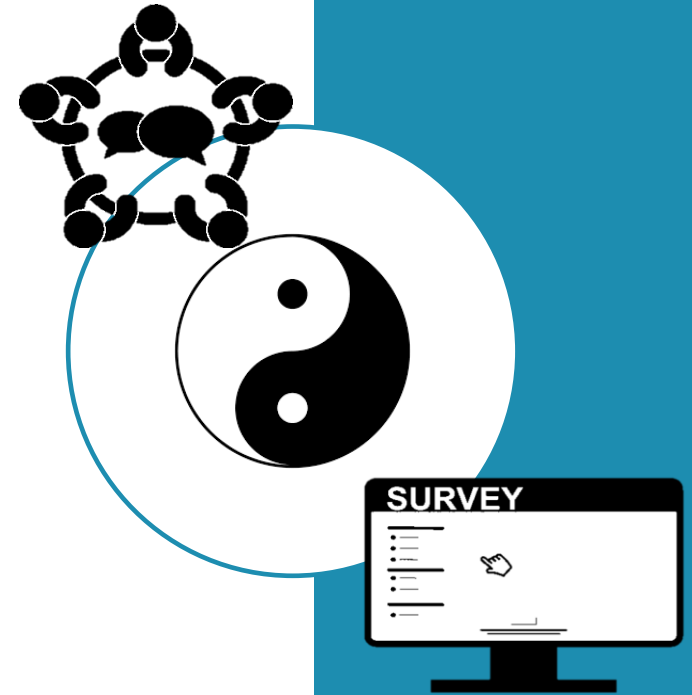
## 2. Ensured **attribute descriptions** were **understandable and clear**

→ Increase patients' understanding and hence internal validity of preference survey findings



# Key take-aways & methodological recommendations for qualitative research in patient preference studies

- Qualitative research provides **complementary data** to quantitative preference research → not one or the other but together to give most comprehensive insights into patients' preferences
- Qualitative research increases relevance and understandability of selected attributes and levels and thereby **increases the internal validity of subsequent preference surveys**
- **Patients and patients' organisations need to be involved** for selection data collection method and **practical organisation** of qualitative research





Thank you

[rosanne.janssens@kuleuven.be](mailto:rosanne.janssens@kuleuven.be)

