# KULEUVEN





# DEVELOPING ATTRIBUTES FOR A PATIENT PREFERENCE SURVEY IN INFLAMMATORY BOWEL DISEASE

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# **BACKGROUND**

As more therapeutic options with their own characteristics (e.g., route of administration, treatment schedule, cost, side effects) become available for inflammatory bowel disease (IBD), individual treatment decision-making, and drug development and evaluation need to be tailored towards patients' preferences and needs. Patient preference studies provide evidence-based information on treatment characteristics that patients consider important and what trade-offs patients are willing to accept.

# **OBJECTIVES**

- > To develop attributes and levels for an IBD patient preference survey using discrete choice experiment
- > To generate experience-based learnings for attribute and level identification in patient preference studies

# **METHODOLOGY**



Scoping literature review: databases and grey literature



Two focus group discussions (n=11) with IBD patients using the nominal group technique



**Descriptive** and qualitative thematic analysis using the framework method



Multi-stakeholder discussions with patients, patient representatives, clinicians, and preference research experts to develop attributes and levels for inclusion in subsequent quantitative patient preference survey

# CONCLUSION

- Defining attributes for inclusion in a subsequent quantitative patient preference study must happen in several steps and include the full integration of patient input.
- This study highlights the importance of incorporating a qualitative portion of a patient preference study to ensure the identification of patient-relevant attributes.
- > This study shows that IBD patients attach great value to symptoms and side-effects that significantly impact their quality of life, such as fatigue, skin problems, and physical changes.
- Eliciting patient preferences for the included attributes may serve pharmaceutical industry, regulators, and payers understanding patient relevant treatment outcomes and can enable value-based and patient-centric decision-making that is aligned with patients' actual needs across the IBD drug life cycle.

# **CONTACT INFORMATION**



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# **RESULTS**

The literature review resulted in the identification of 55 characteristics related to IBD symptoms, side-effects, and efficacy outcomes. These characteristics were further discussed during the focus group discussions and converted into a set of patients' prioritized attributes. The multi-stakeholder discussions reached consensus on 14 attributes, levels, and their descriptions for inclusion in the discrete choice experiment of the quantitative patient preference survey (Table 1 – levels not shown).

**Table 1**. Attributes included in the quantitative patient preference study, not presented in order of importance.



#### Risk of undergoing SURGERY

This is the risk that you need to undergo surgery because: medical therapy cannot adequately control your intestinal inflammation (...).



#### FREQUENCY of having to go to the toilet

This is the frequency that you have to go to the toilet.



#### **URGENCY** and **PAIN** of having to go to the toilet

This is the urgency that you have to go to the toilet and the pain that you experience with it.



#### **Severity of daily ABDOMINAL PAIN and CRAMPS**

This is the severity of abdominal pain and cramps you may experience daily.



## **Severity of FATIGUE**

This is the severity of an overwhelming sense of tiredness, lack of energy, or feeling of exhaustion that is not relieved after rest of sleep.



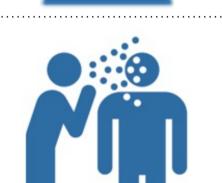
## Frequency of SLEEPING PROBLEMS

This is the frequency you may experience sleeping problems such as difficulty falling asleep, difficulty staying asleep (...).



#### **Severity of PSYCHOLOGICAL IMPACT**

This is the severity of the following psychological impact that you may experience: feeling anxious (...).



#### Risk of SERIOUS INFECTION

This is the risk that you may experience a serious infection. Serious means that they: may have consequences that persist (...).



#### **Duration of severe PHYSICAL CHANGES**

This is the duration that you may experience one of the following changes in your physical appearance: severe weight loss or weight gain (...).



#### **Duration of severe SKIN PROBLEMS**

This is the duration of one of the following severe skin problems that you may experience: dry skin (...).



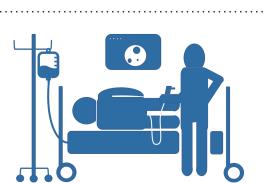
#### **Decreased LIBIDO**

Whether or not you have a decreased libido or sexual desire. This can be caused by: your medication (...).



#### **HOW the tretment is ADMINISTERED**

This is the way that the treatment is administered to you on a regular base.



# **Achievment of long-term ENDOSCOPIC REMISSION**

Whether or not you have visual symptoms of inflammation in your bowels during a medical examination. Endoscopic remission (...).



#### **How FAST the treatment will work**

This is the time between the administration of the medicine and the improvement of the symptoms of the disease. An improvement (...).