



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

- 1** Scoping **literature review**: databases and grey literature
- 2** Two focus group discussions (n=11) with IBD patients using the **nominal group technique**
- 3** **Descriptive** and qualitative **thematic analysis** using the **framework method**
- 4** **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 in 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 (...).