

Patients' Preferences Journey

From Preferences to Outcomes



EFCCA Conference

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EFCCA
European Federation of Crohn's
& Ulcerative Colitis Associations

What are the benefits
of **including patients'**
preferences in the
decision-making
process?



Go on [slido.com](https://www.slido.com)
and enter the code
1141830

What matter most to...

physicians

- Improved **therapeutic outcomes**
- Advanced **drug administration** approach
- Avoiding **surgery**

IBD patients

- Minimizing **fatigue**
- Reducing **abdominal pain**
- Simplifying **treatment administration**

There is very **little scientific evidence** on “patients’ preferences” targeted at the IBD patient community...

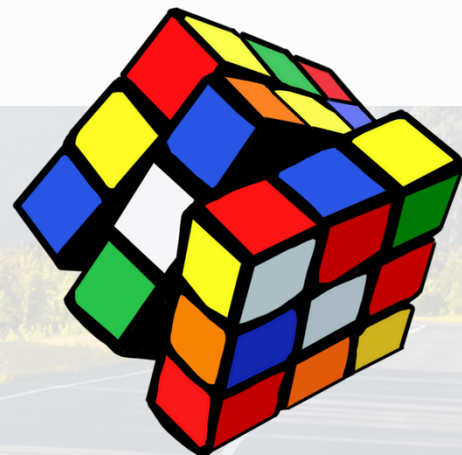
What matter most to IBD patients?

...and still **many questions** to answer.

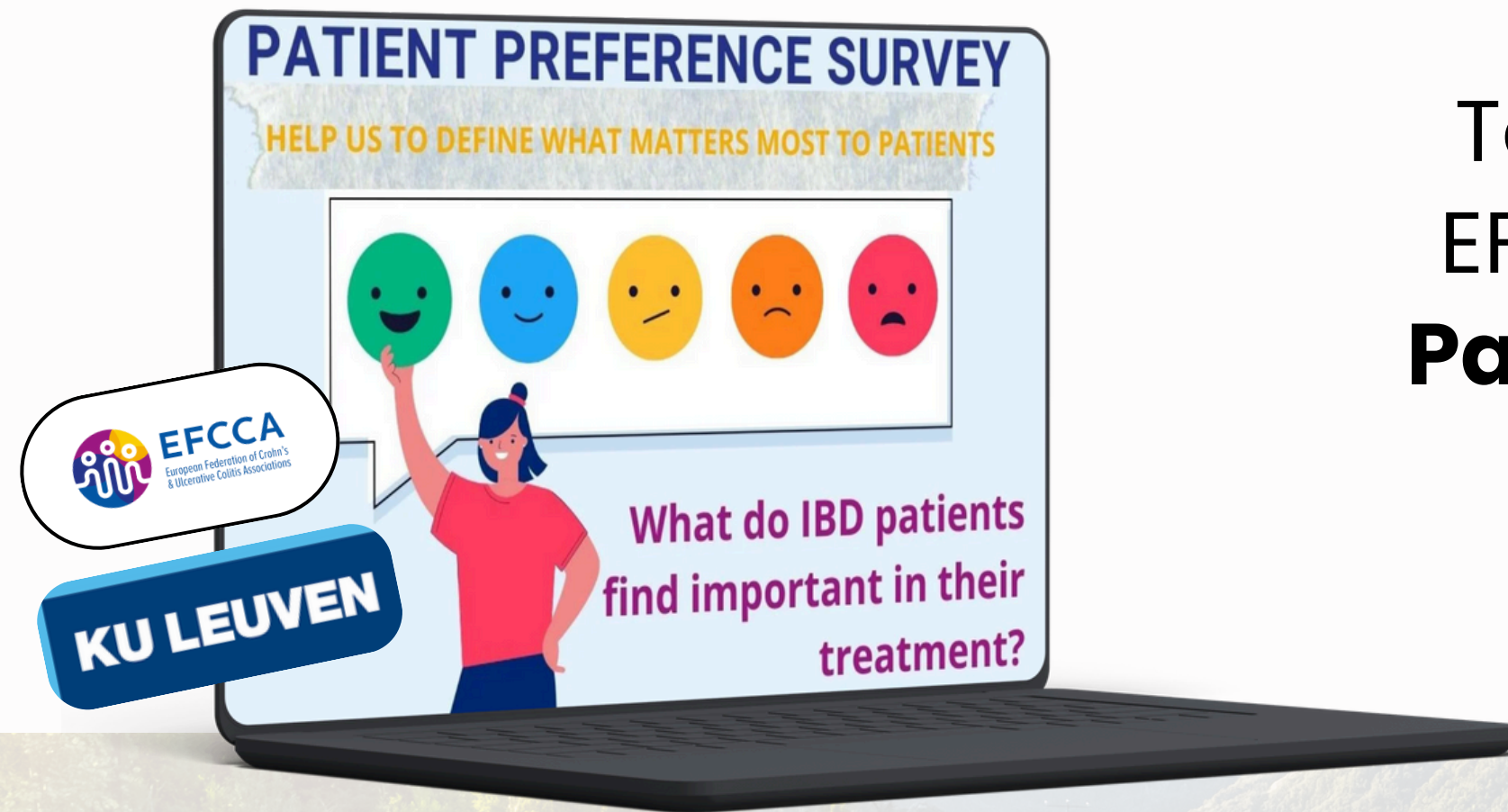
Which **quality of life** effects are important to patients?

Which characteristics should **future drugs** have according to them?

Which **side-effects** do they want to avoid?



What matter most to IBD patients?



To address these questions, EFCCA has embarked on the **Patient Preference Study** with the University of Leuven (**KU Leuven – Belgium**).

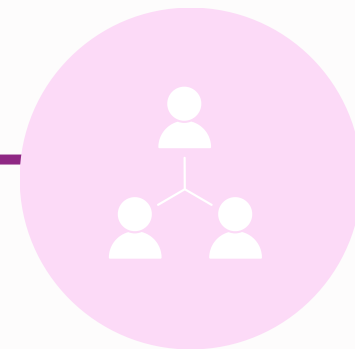
Timeline

2020–2021



Literature review and **first analysis** of collected data and feedback from patient groups

end 2021–begin. 2022



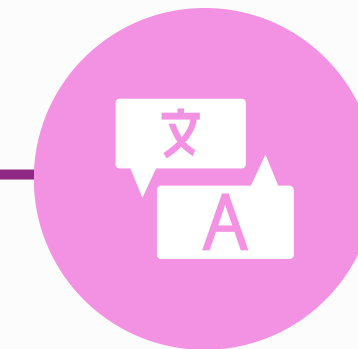
Joint work with KU Leuven on **defining** a quantitative preference survey using Discrete Choice Experiment (DCE)

September 2022



Pilot phase: interviews of native English-speaking patients to gather honest, direct feedback on attributes and the survey

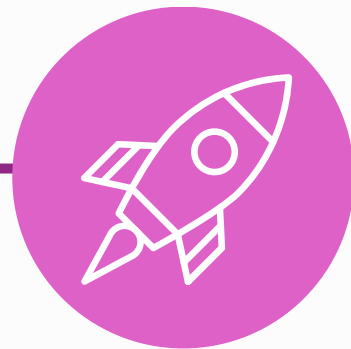
June 2023



Translation to 15 languages

Timeline

July 2023



Launch of
the survey

February 2024



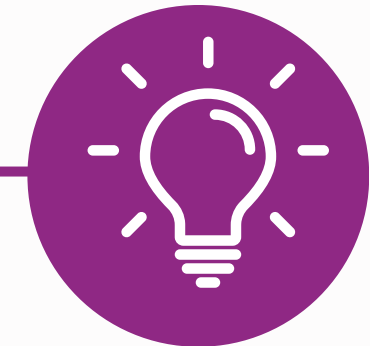
Poster Presentation
with preliminary
Results at **ECCO24**

August 2024



Survey
closed

February 2025



Results presented
at **ECCO25**

Publications



Schoefs, E., Vermeire, S., Ferrante, M., Sabino, J., Lambrechts, T., Avedano, L., Haaf, I., De Rocchis M., Broggi, A., Sajak-Szczerba, M., Saldaña, R., Janssens, R., Huys, I.

“What are the unmet needs and most relevant treatment outcomes according to patients with inflammatory bowel disease? A qualitative patient preference study.”

Journal of Crohn's and Colitis (2022)

Schoefs, E., Vermeire, S., Ferrante, M., Sabino, J., Verstockt, B., Avedano, L., De Rocchis M., Sajak-Szczerba, M., Saldaña, R., Straetemans N., Vandebroek, M., Janssens, R., Huys, I.

“Patient preferences for inflammatory bowel disease treatments: protocol development of a global preference survey using a discrete choice experiment.”

Frontiers in Medicine 11 (2024): 1418874.

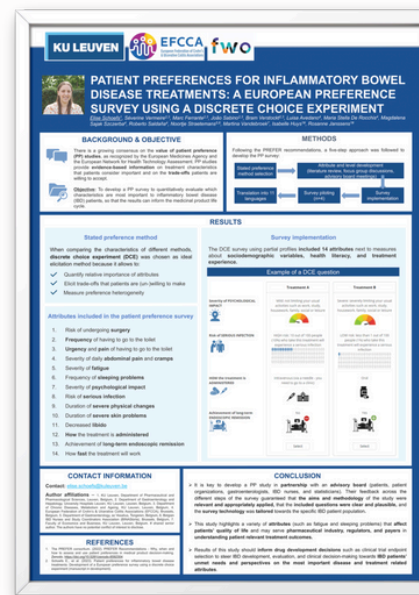
Poster Presentations



Schoefs, E., Vermeire, S., Ferrante, M., Sabino, J., Verstockt, B., Lambrechts, T., Avedano, L., Haaf, I., De Rocchis M., Broggi, A., Sajak-Szczerba, M., Saldaña, R., Janssens, R., Huys, I. (2022)

“Developing treatment attributes for a patient preference study in inflammatory bowel disease.”

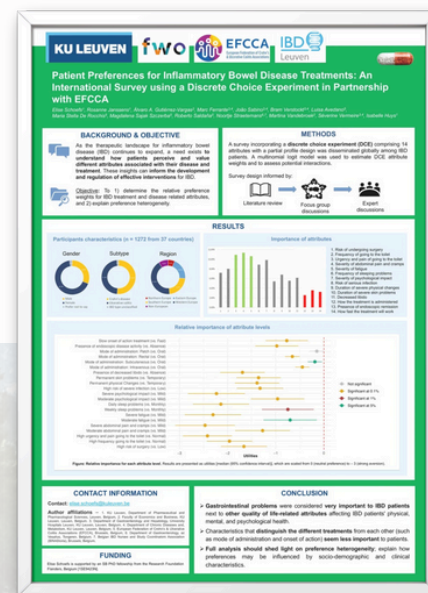
Presented at ISPOR Europe 2022, Vienna, Austria



Schoefs, E., Vermeire, S., Ferrante, M., Sabino, J., Verstockt, B., Avedano, L., De Rocchis M., Sajak-Szczerba, M., Saldaña, R., Straetemans, N., Vandebroek, M., Huys, I., Janssens, R. (2023)

“Patient preferences for inflammatory bowel disease treatments: A European preference survey using a discrete choice experiment.”

Presented at ECCO 2023, Copenhagen, Denmark



Schoefs, E., Janssens, R., Gutiérrez-Vargas, A., Ferrante, M., Sabino, J., Verstockt, B., Avedano, L., De Rocchis M., Sajak-Szczerba, M., Saldaña, R., Straetemans, N., Vandebroek, M., Vermeire, S., Huys, I. (2024)

“Patient preferences for inflammatory bowel disease treatments: An international survey using a discrete choice experiment in partnership with EFCCA.”

Presented at ECCO 2024, Stockholm, Sweden

Development of the study



Literature review



Advisory board discussions



Survey



Development of the study



Literature review



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- Previous patients' preferences studies
- Available IBD treatments
- IBD clinical trials
- Qualitative research findings

(Schoefs et al., *Journal of Crohns and Colitis*, 2022)

Development of the study



Advisory board discussions



An **advisory board** was consulted to:

- discuss survey **aims** and **methodology**
- ensure the questions were **relevant**, **clear** and **feasible** for IBD patients

The board **consisted of:**

- 2 patients • 2 EFCCA patient representatives
- 4 gastroenterologists specialized in IBD
- 1 IBD nurse • 1 statistician

Development of the study



Survey



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Aims of the survey:

- To identify IBD patients' **unmet treatment needs**
- To measure the importance of **key IBD treatment attributes**
- To examine how **patient characteristics** influence preferences

Development of the survey















The survey consisted out of 10 parts:

- 1) Language selection
- 2) Introduction
- 3) Screening questions
- 4) Information sheet and informed consent form
- 5) Explanation of attributes and levels included
- 6) DCE questions
- 7) Feedback on DCE questions
- 8) validation question
- 9) Questions on patients socio-demographic characteristics, clinical characteristics and contextual factors
- 10) Survey evaluation questions

Development of the survey

Survey questions:

- Multidisciplinary **advisory board meetings** and **revision rounds**
- Final list: **14 attributes** related to IBD patients treatment or disease.

	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 treatment is ADMINISTERED This is the way that the treatment is administered to you on a regular base.
	Achievement 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 (...).

- Additionally, for each attribute, a comprehensive **range of 2 to 5 levels** was established.

Development of the survey

Question (1 out of 15)

Imagine that you and your gastroenterologist are discussing treatments for your inflammatory bowel disease. Your gastroenterologist thinks that there are two possible treatments you could consider: treatment A and treatment B. Treatment A and treatment B have different characteristics and results.

Should your gastroenterologist present the two treatments below, would you prefer treatment A or treatment B, according to the characteristics and results of the given treatments?

You can read more information about the different characteristics by dragging your cursor over the characteristics if you are using a laptop or computer or by clicking on them if you are using a tablet or smartphone.

	Treatment A	Treatment B
Risk of undergoing SURGERY	HIGH risk: 10 out of 100 people (10%) who take this treatment will need surgery	HIGH risk: 10 out of 100 people (10%) who take this treatment will need surgery
FREQUENCY of having to go to the toilet	High frequency, more as prior to the diagnosis of inflammatory bowel disease	Normal frequency, similar as prior to the diagnosis of inflammatory bowel disease
Severity of daily ABDOMINAL PAIN and CRAMPS	Severe abdominal pain and severe cramps	No abdominal pain and no cramps
How FAST the treatment will work	Fast reduction of symptoms (within first 2 weeks after starting the treatment)	Slow reduction of symptoms (3 months after starting the treatment)

0% 100%

Do not hesitate to email info@efcca.eu for any assistance in completing this survey

- The 14 attributes were included in DCE (Discrete Choice Experiment) questions
- Patients choose between two hypothetical treatments (A & B)
- 15 of these DCE questions were then included in the survey next to background questions on:
 - socio-demographic characteristics
 - contextual factors
 - disease and treatment related characteristics

Piloting

The survey was piloted with four native **English-speaking patients**

Feedback from each interview was discussed with the advisory board until **consensus** was reached

Piloting **concluded after the 4th interview**, as no further changes were needed

Online pilot interviews used the **think-aloud method** to assess:

- **Comprehensibility** of general questions
- Understanding of **choice questions, attributes** and **descriptions**
- **Choice behaviour**
- Survey **length**

CROHN'S & COLITIS UK

We thank **Crohn's & Colitis UK** for its collaboration!

Translations

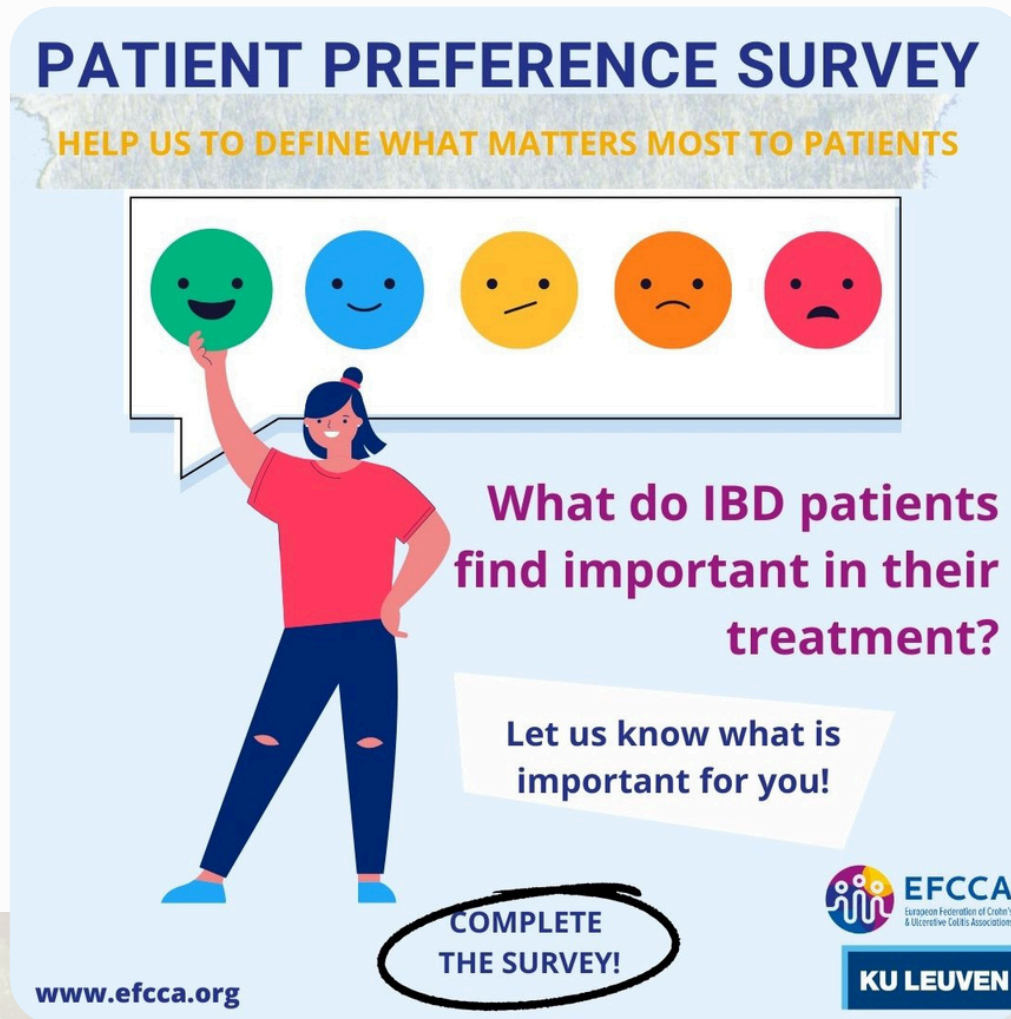
The survey is available in **15 languages**



- Arabic
- Croatian
- Danish
- Dutch
- English
- Finnish
- French
- German
- Greek
- Hungarian
- Italian
- Polish
- Portuguese
- Romanian
- Spanish

**Thanks to our all of our members
who helped us with the
translations!**

Overview



PATIENT PREFERENCE SURVEY
HELP US TO DEFINE WHAT MATTERS MOST TO PATIENTS

What do IBD patients find important in their treatment?

Let us know what is important for you!

COMPLETE THE SURVEY!

www.efcca.org

EFCCA
European Federation of Crohn's & Ulcerative Colitis Associations

KU LEUVEN

The graphic features a woman in a red shirt and blue pants pointing to a row of five colored smiley faces (green, blue, yellow, orange, red) representing a Likert scale. The background is light blue with a white speech bubble containing the survey question.

- Launched in July 2023 until August 2024
- Online, web-based survey
- Available in 15 languages in 46 countries
- Addressed to +18 IBD patients
- Distributed through national IBD associations

What are the benefits of **including patients' preferences** in the decision-making process?

Back to the initial question...

From our two Guidebooks

Informing Regulatory Decisions: Patient preference data help regulators understand which treatments are most suitable for individual patients, influencing benefit-risk assessments and approval decisions.



Development of treatments and therapies that better meet **patients' needs**

Improved **treatment outcomes** and **quality of life** for patients

Development of **safer** and **more effective** treatments

Potential **risks** and **side effects** can be addressed early on

From our two Guidebooks



Aligning with Patient Values: Patients value therapies based on their perceived efficacy, safety profiles and the impact on their daily lives. Including these preferences ensures that treatment outcomes align with what patients find most important.

This approach ensures that the chosen treatment reflects **what the patient finds most important**, rather than relying solely on clinical metrics.

Treatments are more likely to be **accepted** and **adhered to** by patients

Less **time** and **resources** on treatments that may not meet patient needs

From our two Guidebooks



Complementing Patient-Reported Outcomes (PROs):
While PROs provide information about patients' feelings and daily functioning, preference studies offer insights, including treatment characteristics and benefit-risk compromises they are willing to accept (PREFER Patients Preferences, 2023).

Potential **risks** and **side effects** can be addressed early on

Results contribute...

- To have a **general picture** on the patients' preferences at European level and beyond
- To have country data for comparison on **how to support patients** in clinical practice
- To assist national associations in **advocating** for their needs

Looking Ahead

In the same direction, EFCCA is committed to offering the IBD community valuable **insights** and **support**:



- sharing national **reports** with its national members and providing **guidance** to help them interpret the data effectively.
- assisting them in **maximising** these findings and supporting them in integrating the data to drive **impactful decisions**.

Thanks and Acknowledgements

A great thank you to all **the patients** who took part and to **the national IBD associations** for their invaluable support in this study!



Thank you!



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