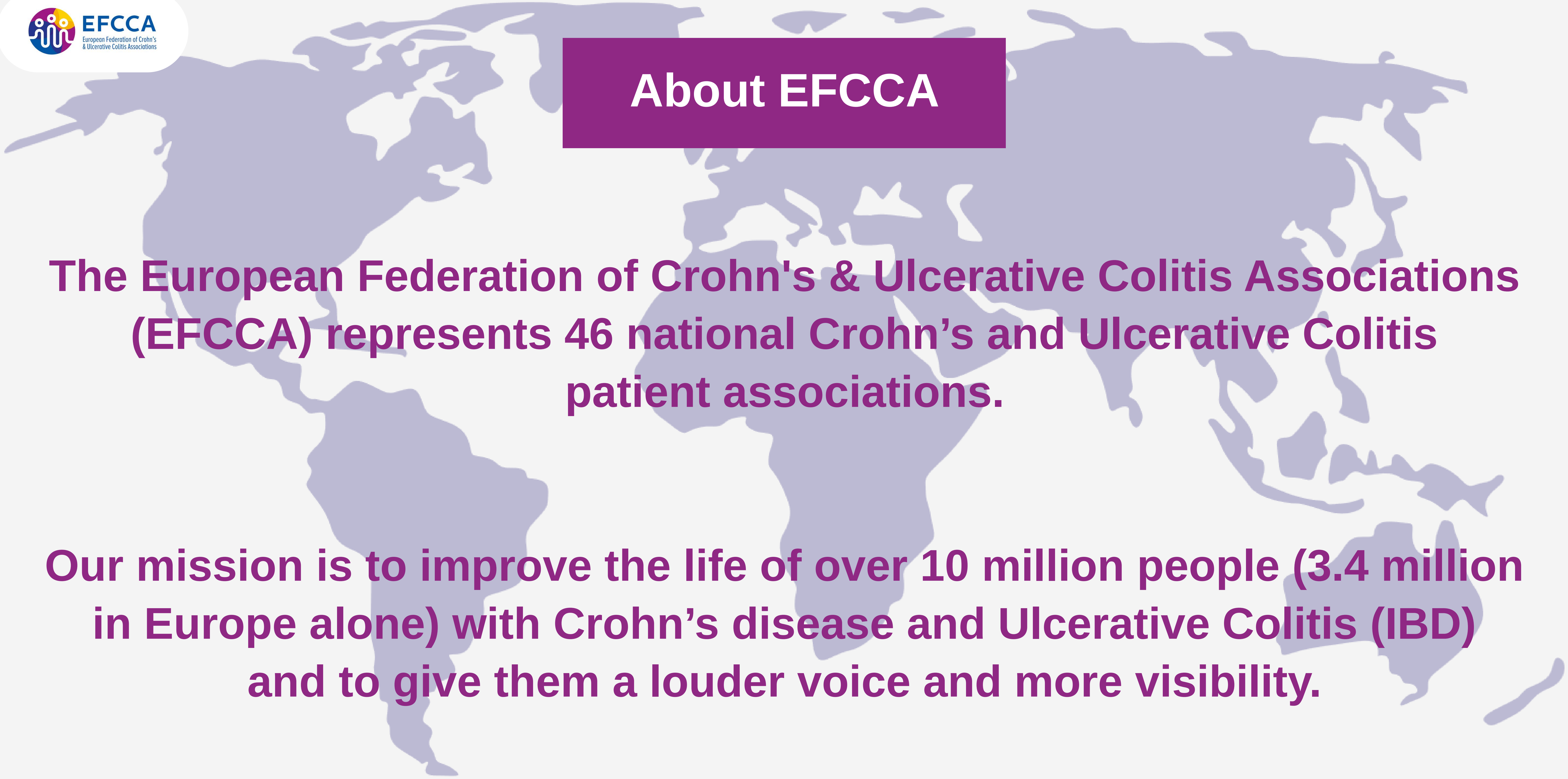
Patient Preferences Study: Our Contribution as a Patient Organisation

ISPOR Europe

Copenhagen, 14 November 2023

EFCCA
European Federation of Crohn's
& Ulcerative Colitis Associations

Maria Stella De Rocchis
Project Coordinator



About EFCCA

The European Federation of Crohn's & Ulcerative Colitis Associations (EFCCA) represents 46 national Crohn’s and Ulcerative Colitis patient associations.

Our mission is to improve the life of over 10 million people (3.4 million in Europe alone) with Crohn’s disease and Ulcerative Colitis (IBD) and to give them a louder voice and more visibility.

EFCCA
European Federation of Crohn's & Ulcerative Colitis Associations

“We believe that patients should be given **the best possible treatment options** not only in quality of care but also quality of life, allowing them to **live their life to the fullest**.”

Which are the **benefits** of incorporating **patient preferences** throughout the product life-cycle?

(polling question)

Benefits

- The development of treatments and therapies that **better meet patients' needs**
  - Improved treatment outcomes and quality of life for patients
- The development of **safer** and **more effective** treatments
  - Potential risks and side effects can be addressed early on

Benefits

- To bridge the gap **between patients and researchers**, fostering a sense of partnership and shared responsibility
  - Patients are empowered and valued, leading to increased trust and collaboration
- Treatments that are more likely to be **accepted and adhered to** by patients
  - Less time and resources on treatments that may not meet patient needs

Facing PPS challenges

- Facilitating the **dialogue** between researchers and patients / Establishing **trust** between patients and researchers

How we addressed this:

- Inclusion since the initial stages of the study / Partnership at the same level
- Communication clear and understandable
- Close collaboration among EFCCA, KU Leuven and IBD Patients

Facing PPS challenges

- Ensuring a **patient-friendly survey language** for broad understanding, attributes and levels are **meaningful and relevant** to patients

How we addressed this:

- Alternative vocabulary / Simplified language
- Understandability of questions and attributes at each stage
- Medical vs patient friendly terms

Facing PPS challenges

- Understanding patient community **needs and concerns**, accounting for age, personal traits, and location variances

How we addressed this:

- Survey translated into 14 different languages
- Personal / medical experience brought into the study design
- Participation in pilot, recruitment: patient organisations + clinicians

How to maximize findings

- Findings will help us to achieve a general picture on the patient preferences at European level and analysing country data for comparison on how to support patients in clinical practice
- Results are helpful to standardise clinical trial protocols, support sponsors in achieving this goal, create standard guidelines

How to maximize findings

- In the same direction, EFCCA is committed **to offer** the IBD community:
  - **Trainings** to provide with targeted education, competence, and information in order to **improve knowledges** around the disease and to **better advocate**
  - **Practical toolkit** on how to assist sponsors and health authorities in bringing **new medicines** to the market and making **better decisions**

Q&A

Can you tell us more about the last two examples of empowerment efforts that EFCCA is implementing?

Any questions?

mariastella.derocchis@efcca.org

EFCCA
European Federation of Crohn's
& Ulcerative Colitis Associations

Thank you!