



## FEATURED

[Abstract](#)   [Discussion Forum \(0\)](#)
**Number: Mo1964**

THE IBD LIFE QUESTIONNAIRE: WORLD-WIDE DEVELOPMENT AND VALIDATION AND INTERCONTINENTAL DIFFERENCES OF NORMAL LIFE IMPAIRMENT

**Society:** AGA**Track:** Inflammatory Bowel Diseases**Author(s) and Affiliation(s):**

Joep Oostrom<sup>1</sup>, Suzanne Irene Anjie<sup>1</sup>, Juan Sebastián Lasa<sup>2</sup>, Neda Karimi<sup>3</sup>, Jamie Horrigan<sup>4</sup>, Heena Sareen<sup>5</sup>, Bhargavi Adi<sup>6</sup>, Girish Ganesh<sup>6</sup>, Suk-Kyun Yang<sup>7</sup>, Laura Parks<sup>8</sup>, Christian Broër<sup>9</sup>, Anja de Kruif<sup>10</sup>, Laurent Peyrin-Biroulet<sup>12</sup>, Byong Duk Ye<sup>7</sup>, Rupa Banerjee<sup>6</sup>, Pablo Olivera Sendra<sup>11</sup>, Corey A. Siegel<sup>4</sup>, Susan Jane Connor<sup>5</sup>, Krisztina Gecse<sup>1</sup>, Geert D'Haens<sup>1</sup>

1. Gastroenterology and Hepatology, Amsterdam UMC Locatie VUmc, Amsterdam, Noord-Holland, Netherlands. 2. IBD Unit, Gastroenterology Section, Department of Internal Medicine, Centro de Educación Médica e Investigación Clínica (CEMIC, Buenos Aires, Argentina. 3. South West Sydney Clinical Campuses, UNSW Medicine and Health, UNSW Sydney, Sydney, Australia and South Western Sydney IBD Research Group, Ingham Institute for Applied Medical Research, Sydney, NSW, Australia. 4. Dartmouth Hitchcock Medical Center, Lebanon, NH, United States. 5. Department of Gastroenterology, Liverpool Hospital, Sydney, NSW, Australia. 6. Asian Institute of Gastroenterology, Hyderabad, Telangana, India. 7. Asan medical center, University of Ulsan College of Medicine, Seoul, Korea (the Republic of). 8. Gastroenterology Department, Hospital Británico, Buenos Aires, Argentina. 9. Faculty of Sociology, University of Amsterdam, Amsterdam, Netherlands. 10. Faculty of Science, Methodology and Applied Biostatistics, Free University, Amsterdam, Netherlands. 11. Zane Cohen Centre for Digestive Diseases, Lunenfeld-Tanenbaum Research Institute, Sinai Health System, Toronto, ON, Canada. 12. Department of Gastroenterology, University of Lorraine, CHRU-Nancy, Nancy, France.

**Background**

For patients with inflammatory bowel diseases (IBD), the ultimate goal is to live a "normal life"™, yet no validated patient-reported outcome measure (PROM) exists to assess this. We aimed to develop and validate a globally relevant PROM to assess the impact of IBD on normal life through a world-wide, patient-centered approach, the "IBD LIFE"™.

**Methods**

Patients with Crohn's disease (CD) or ulcerative colitis (UC) from Argentina, Australia, India, the Netherlands, South Korea, and the USA without ostomies, pouches, or significant comorbidities were eligible. The development phase involved (A) patient interviews, (B) a Delphi consensus, (C) patient focus groups, (D) pilot-testing, and (E) cross-cultural translation, resulting in a 23-item PROM with five domains: physical, activities, social, psychological, and circumstances.

For the validation phase, CD and UC patients speaking Dutch, English, Spanish, Hindi, and Korean were recruited (n=100 per disease, per language). IBD LIFE and generic and IBD-specific quality of life (QoL) PROMs ((Short-Form-36 (SF-36) and IBD Questionnaire (IBDQ)) were administered at baseline, 2 weeks (n=30 per language) and 8 weeks. Clinical disease activity was measured at baseline and 8 weeks using (Harvey Bradshaw Index (HBI) for CD and Simple Clinical Colitis Activity Index (SCCAI) for UC). Construct validity was tested through correlations between baseline indices, repeatability using intraclass correlation coefficient (ICC) in patients with stable QoL at 2 weeks, and responsiveness through a Receiver Operating Characteristic curve analysis for detection of clinically meaningful change in IBDQ at 8 weeks. Country-specific normal life impairment patterns were assessed using total IBD LIFE scores and domain weights.

**Results**

Among 605 patients (300 CD/305 UC, table 1), IBD LIFE's construct validity was supported by strong correlations with QoL indices (IBDQ r=-0.90; SF-36 r=-0.83), and moderate correlations with clinical disease indices (HBI r=0.52; SCCAI r=0.51). IBD LIFE showed strong repeatability (ICC=0.91) and responsiveness (AUC=0.873).

IBD LIFE scores ranged from 0-90 (mean 18.51 ± 18.73), with higher scores being associated with more impairment on normal life. Physical and psychological domains had most impact on patients' lives (indicated by highest domain weights, figure 1). USA patients had the lowest IBD LIFE score compared to other countries (mean 12.27 ± 14.20; P<0.001), yet showed disproportionately higher impact in the physical domain and lower impact in activities (Figure 1).

**Conclusion**

IBD LIFE, developed with extensive patient involvement, is a valid PROM of IBD's impact on normal life and allows tailored patient support to achieve normal life across all life domains affected by IBD.

## THE IBD LIFE QUESTIONNAIRE: WORLD-WIDE DEVELOPMENT AND VALIDATION AND INTERCONTINENTAL DIFFERENCES OF NORMAL LIFE IMPAIRMENT

Krisztina Gecse

DDW ePoster Library. Gecse K. 05/05/2025; 4153851; Mo1964


[Abstract](#)   [Discussion Forum \(0\)](#)


Number: Mo1964

THE IBD LIFE QUESTIONNAIRE: WORLD-WIDE DEVELOPMENT AND VALIDATION AND INTERCONTINENTAL DIFFERENCES OF NORMAL LIFE IMPAIRMENT

READ MORE

## About Us

Digestive Disease Week® (DDW) is the world's premier meeting for physicians, researchers and industry in the fields of gastroenterology, hepatology, endoscopy and gastrointestinal surgery.

## Follow us



2025 © Digestive Disease Week®

[USER TERMS AND CONDITIONS](#) / [PRIVACY POLICY](#)  
(Amended according to GDPR)