

DIIMentoring Project – Patient Associations as a Catalyst for Quality-Of-Life Improvement In Inflammatory Bowel Disease



Sampaio A¹, Pais J¹, Fernandes I², Cardoso P³, Sousa J³

1) APDI – Associação Portuguesa da Doença Inflamatória do Intestino, Matosinhos, Portugal 2) Portugal Human Design School, Porto, Portugal 3) MOAI Consulting, Lisbon, Portugal

Context and objectives

Inflammatory bowel disease (IBD), poses a significant burden on patients' physical, emotional, and social well-being. In Portugal, IBD prevalence is estimated at 24,069 patients, with 6,067 DALYs estimated to be lost in Portugal due to IBD (1). Beyond clinical management, **peer support programs can help patients navigate the challenges of living with a chronic illness** (2).

The **DIIMentoring Project** was launched in 2020 by APDI (Portuguese Association of Inflammatory Bowel Disease) as an **informal support and mentoring program for people with IBD**, connecting individuals recently diagnosed with IBD (mentees) with experienced patients (mentors). This structured program aimed to promote **effective disease self-management** and the improvement of quality of life (QoL).

The main objective of this work is to **evaluate the program's impact across various QoL dimensions** and to **estimate its effect on disease control**.

Methods

Participants completed a baseline clinical and demographic questionnaire, along with the **SF-36 MOS**, **HADS** (Hospital Anxiety and Depression Scale), and **PSS-10** (Perceived Stress Scale) questionnaires, which were administered electronically, using google forms, annually through year 4. Disease control and perceived severity were also collected through Likert-based questions. SF-36 scores were calculated for each domain and also converted to **EQ-5D** index scores using the algorithm validated by Rowen et al. (3). A mixed-effects model was fitted to baseline covariates, with the EQ-5D index score as the dependent variable.

Results

Until 2025, **59 participants** were included in the program. Most mentees were female (85%); 44% had ulcerative colitis, 51% Crohn's disease, and 5% unspecified colitis. The median disease duration was 1 year (Table 1).

Table 1 | Baseline characteristics of study population

	Frequency	%
Gender		
Male	8	13.56%
Female	51	86.44%
Disease		
Ulcerative Colitis	26	44.07%
Chron Disease	30	50.85%
Unspecified Colitis	3	5.08%
Age at diagnosis (Median)	33 (16-69)	
Age at project start (Median)	35 (18-73)	
Time from diagnosis (years - Median)	1 (0-24)	
Adherence (N follow-up questionnaires)	72	65,69%
Reported disease severity (Average)	3.1	

After the first year, participants referred demonstrated a **0.12-unit increase in the EQ-5D index score** - 0.62 vs 0.74 (Wilcoxon, $p < 0.05$). Initial disease severity ($\beta = -0.079$, $p < 0.001$) and baseline disease control ($\beta = -0.057$, $p < 0.001$) were the only factors that significantly impact QoL improvement (Figure 2)

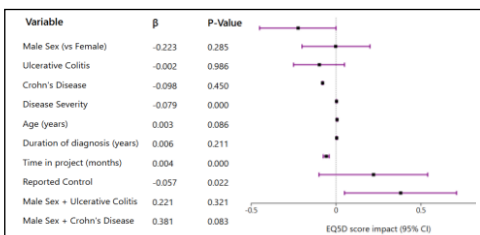


Figure 2 | Mixed effects linear regression of baseline factors with EQ5D index score after one year

All evaluated QoL dimensions improved after the beginning of the program; this increase was significant ($p < 0.05$) by year 3, particularly in emotional health (+46), physical health (+29) and vitality (+23).

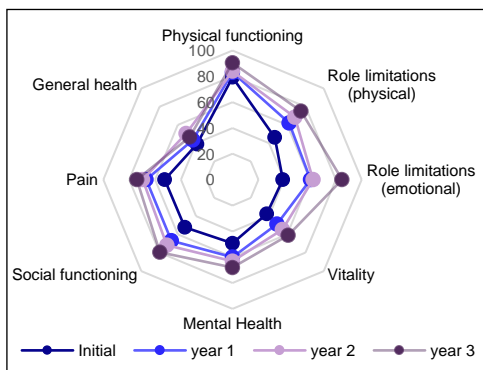


Figure 1 | SF-36 score by domain, from baseline to year 3 (100 represents the best score)

At baseline, 14% of the mentees presented uncontrolled disease. **After two years, disease control improved in 77% of these participants.**

In the beginning of the program, 27% of all participants presented with depressive symptoms (measured by the HADS tool). After 3 years in the program, **only 9% of participants had depressive symptoms** (a 67% decrease).

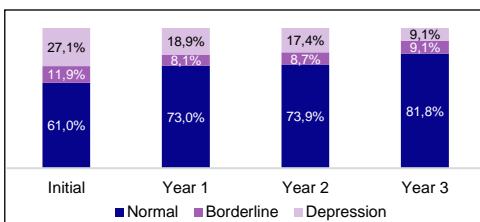


Figure 3 | Depression evaluation through HADS tool

After 3 years all participants stated that **the program contributed to a better disease management.**

Discussion

The DIIMentoring Project improved QoL, emotional health, and disease control in IBD patients. Baseline severity and disease control influenced outcomes. **Participant satisfaction and demonstrated improvements suggest that mentoring is a feasible and effective adjunct to standard clinical care.** Such structured initiatives, developed by Patients Associations, demonstrate the benefit of multistakeholder cooperation in IBD management.

References

- Magro F, Pontes F, Lago P, et al. Burden of Disease and Cost of Inflammation of Inflammatory Bowel Diseases in Portugal. GE Port J Gastroenterol. 2022;30(4):283-292. Published 2022 Jun 15. doi:10.1159/000525206
- Pollock MD, Brodin SM, Deno E, et al. Clinical application of a peer coaching intervention to enhance self-management for adolescents and young adults with inflammatory bowel disease. Clinical Practice in Pediatric Psychology. 2022;10(4):409-427. doi:https://doi.org/10.1037/cpp0000468
- Rowen D, Brazner J, Roberts J. Mapping SF-36 onto the EQ-5D index: how reliable is the relationship?. Health Qual Life Outcomes. 2009;7:27. Published 2009 Mar 31. doi:10.1186/1477-7525-7-27

Funding and Disclosures

Financial support for the mentoring program was provided by Takeda Farmacêuticos Portugal, which had no input in the content or conclusions.

