

The real-world global use of patient-reported outcomes (PROs) for the care of patients with IBD

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BACKGROUND

- Many PROs have been developed for use in inflammatory bowel disease (IBD) care without clear recommendations for use
- PROs differ from physician-reported disease activity indices; they assess patients’ perceptions of their symptoms, functional status, mental health, and quality of life, among other areas
- We sought to investigate the current global use and barriers to using PROs in clinical practice for IBD

METHODS

- A cross-sectional survey was performed
- Members of the International Organization for the Study of Inflammatory Bowel Disease (IOIBD) were invited to participate and invite regional colleagues
- Results are reported using simple descriptive statistics

Table 1. Demographics of questionnaire respondents

Provider Demographics	N	%
Overall	194	
Degree		
MD/DO/equivalent	179	92.3%
Advanced Practice Providers	5	2.6%
Other	19	5.2%
Years of Experience Post Training		
<5 years	31	16%
5-10 years	25	12.9%
>10 years	138	71.1%
Specialty		
Adult GI	135	69.6%
Pediatric GI	11	5.7%
Colorectal Surgery	44	22.7%
Other	4	2.1%
Type of Practice		
Academic Medical Center	123	63.4%
Hospital-based Practice	57	29.4%
Private Practice	10	5.2%
Other	4	2.1%
Volume of IBD Patients seen per week		
<10 patients	56	28.9%
10-20 patients	54	27.8%
>20 patients	84	43.3%
Continents Represented		
Asia ^a	78	40%
Europe ^b	60	31%
North America ^c	35	18%
Oceania ^d	12	6%
South America ^e	10	5%

a: Japan, India, Bangladesh, Singapore, Vietnam, Malaysia, Burma, China, Kuwait, Nepal, Qatar
b: United Kingdom, Sweden, Greece, Belgium, Ireland, Italy, Norway, Spain, Germany, Switzerland, Portugal, Austria, Czech Republic, Jersey, Netherlands
c: United States, Canada, Mexico
d: Australia, New Zealand
e: Brazil

Table 2. Suggested PRO tools to be used in clinical practice for the care of patients with IBD

Patient-Reported Outcome (PRO) Tool	Proportion of Providers Recommending each PRO Tool (%)
PRO2 or PRO3	15.41
Simple clinical colitis activity index (SCCAI)	14.86
Patient Reported Harvey Bradshaw Index (HBI)	14.59
Survey Index CDAI	10.81
Short IBDQ	10.27
IBD Disk	7.30
IBD Control	4.05
Facit-Fatigue Scale	4.05
Other	3.78
Short Health Scale	3.24
EQ-5D-5L	2.70
General Psychological Well-Being Score (GPP)	2.43
Manitoba Inflammatory Bowel Disease Index	2.43
Work Productivity & Activity Impairment Questionnaire (WPAI)	1.89
PROMIS-10	0.01
ICHOM Standard Set	0.01

* Providers were allowed to respond to more than 1 PRO tool

RESULTS

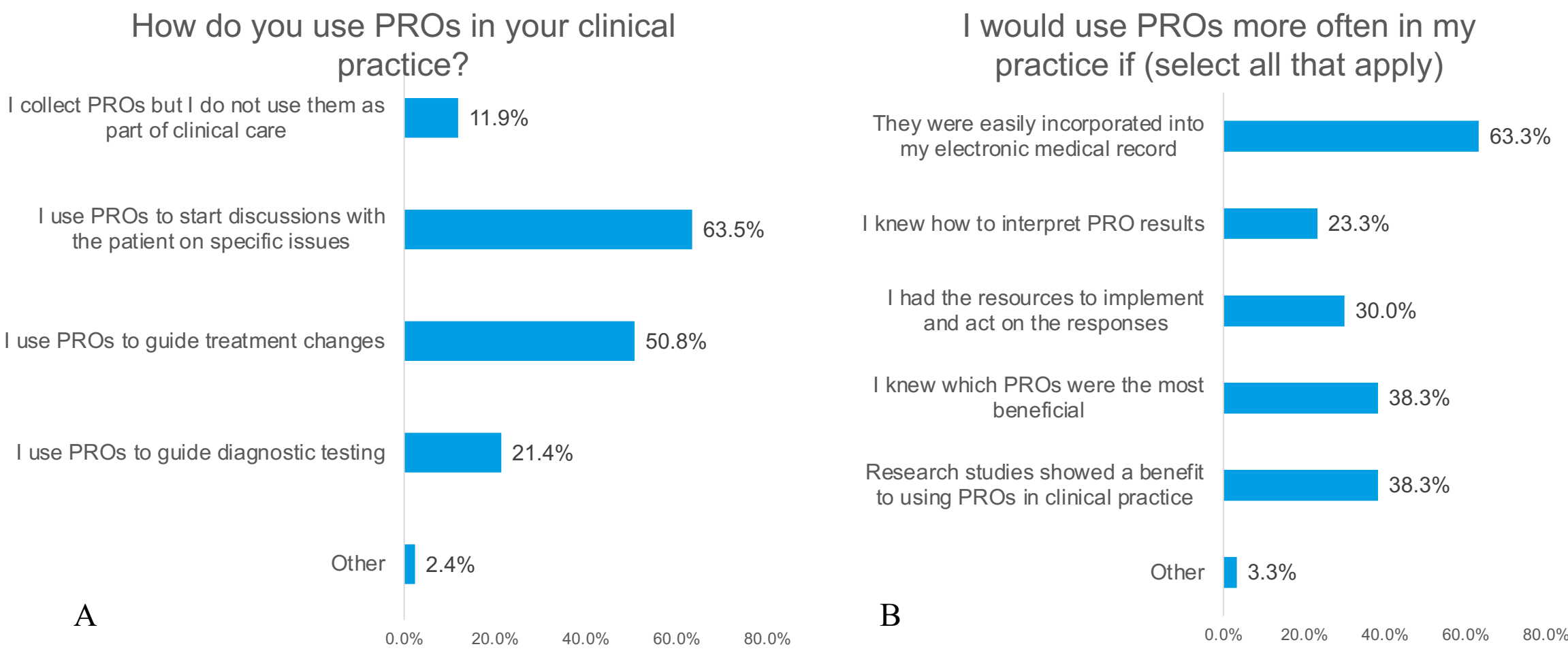


Figure 1. Provider perceptions of using PROs in clinical practice. (A) How PROs are used in clinical practice. (B) Reasons why providers would use PROs more often.

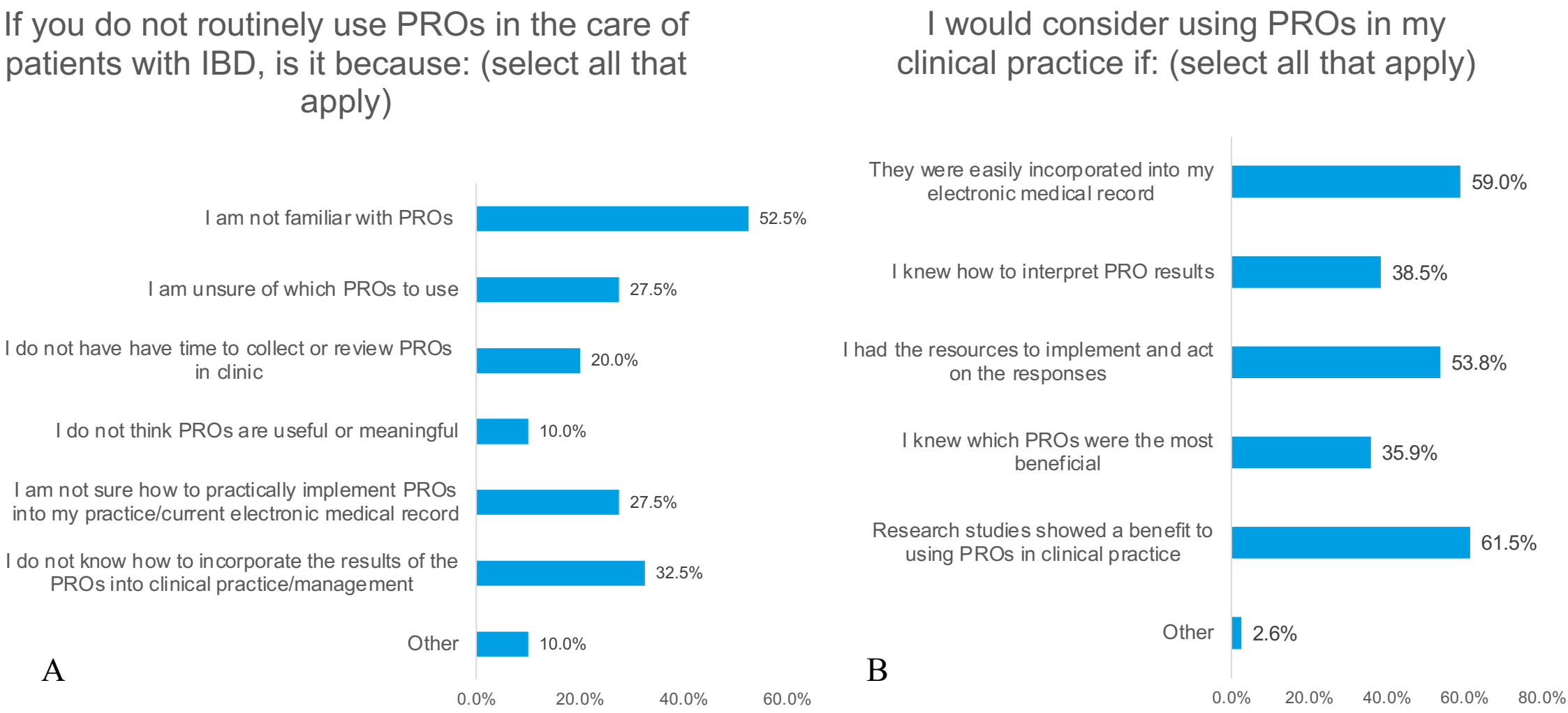


Figure 2. Providers who do not routinely use PROs. (A) Reasons why providers do not use PROs in clinical practice. (B) Scenarios in which they would consider using PROs.

- There were 194 respondents, including adult/pediatric gastroenterologists, advanced-practice providers, and colorectal surgeons from 5 continents
- The majority (80%) currently use PROs in clinical practice, 65% frequently found value in routine use, and 50% frequently found PROs influenced management
- 31 different PROs for IBD were reportedly used. Barriers included not being familiar with PROs, not knowing how to incorporate results into practice, and time constraints
- Providers who did not use PROs had more years of experience and spent more time with patients during the first visit
- Most participants (91%) agreed it would be beneficial to have an accepted set of PROs used consistently
- Half thought that the currently available PROs were acceptable, and 10% responded that a new PRO was needed
- The majority (60%) thought that there should be some cultural differences in PROs used globally but that PROs for IBD should be fairly consistent around the world.

DISCUSSION

- PROs are used frequently in clinical practice with wide variation in which PROs are used and how they influence patient management
- Education around how to use and interpret an accepted set of PROs could allow for global harmonization