

WHAT IS "RECOVERY"?

PATIENT-CENTERED RECOMMENDATIONS FOR COMPLEX TERMINOLOGY IN PROs



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OBJECTIVE:

Clear and concise terminology in patient reported outcome assessments (PROs) is essential to ensure patient comprehension and high-quality data collection.

Linguistic validation (LV) work shows the term "in recovery" to be problematic for patients and linguists due to its ambiguity, with undefined specifications of time (duration), symptom severity, and treatment involvement.

Here we focus on comprehension issues related to the phrase "in recovery" within an Ulcerative Colitis screener. Ulcerative Colitis is an incurable disease but is officially considered "in remission" when symptoms have subsided.

Our goals are to provide guidance for improving usage of the phrase 'in recovery' and its more general construct in PRO development, and add to a growing body of work focused on conceptually ambiguous terms used in PROs and methods to improve PRO development and translatability.

METHODS:

We reviewed linguist and patient feedback on the phrase "in recovery" across 36 PRO translations, involving 28 languages (See Table 1).

Respondents (n=180) were 18-85 years old, with 7-20 (average = 12.3) years of education.

Table 1

Languages		Languages	
1	Assamese	15	Latvian
2	Bengali	16	Marathi
3	Bosnian	17	Polish
4	Bulgaria	18	Punjabi
5	Croatian	19	Romanian
6	Czech	20	Russian
7	English	21	Serbian
8	Georgian	22	Sinhala
9	Greek	23	Slovak
10	Gujarati	24	Spanish
11	Hindi	25	Tamil
12	Hungarian	26	Telugu
13	Italian	27	Ukrainian
14	Kannada	28	Urdu

Table 2

Probe Question	
1.	What is your definition of "in recovery"?
2.	If you were "in recovery" of ulcerative colitis, would you still be experiencing symptoms?

RESULTS:

Out of 180 interviews, 54% (n=98) of respondents considered "in recovery" as a process, involving an extended period prior to full recovery. 46% (n=82) of respondents interpreted "in recovery" as an end point or final stage of illness (See Figure 1).

Figure 1: What and when is "recovery"?



In our qualitative analysis, we extracted a number of codes that provide insight into the subject's responses. In Table 3, example codes are provided to illustrate how participants defined "in recovery". A range of feedback was collected; we present some examples here. When asked about their experience with symptoms "in recovery", those who thought symptoms would persist (54% of total respondents) spoke to their frequency and severity. A Croatian respondent said their symptoms would be "less frequent" and a Latvian respondent said their symptoms would "occur less often". Other respondents viewed "in recovery" as an improvement in symptom severity. 3 Czech respondents thought symptoms

would be "negligible" or "very little". All Mexican respondents (n=5) agreed that symptoms would be "not as bad" or "getting better".

Other codes defining "in recovery" include treatment and flare ups. Regarding treatment, respondents mentioned that their symptom improvement would be mostly or entirely due to an effective treatment plan. Those who mentioned flare ups explained that a chance for sudden symptom recurrence and hospitalization is ever-present. These codes lend themselves to the clinical features of UC, particularly its chronic nature. Many patients rely on medication to mitigate their illness and understand that a flare up is still a potential adverse event despite treatment. In fact, 70% (n=122) of respondents believed symptoms would persist "in recovery" (See Figure 2).

Table 3

Example Codes	Definition	Count
Symptoms-frequency	Symptoms are rare; considered to be an improvement from before recovery period	17/180 (9%)
Symptoms-severity	Symptoms are less serious; gets better but not completely; not as bad	29/180 (16%)
Treatment	Actively receiving care; prescriptions, medication, therapy	29/180 (16%)
Flare up	May lead to hospitalization; symptoms come back	9/180 (5%)

Figure 2: If you were "in recovery" of ulcerative colitis, would you still be experiencing symptoms?

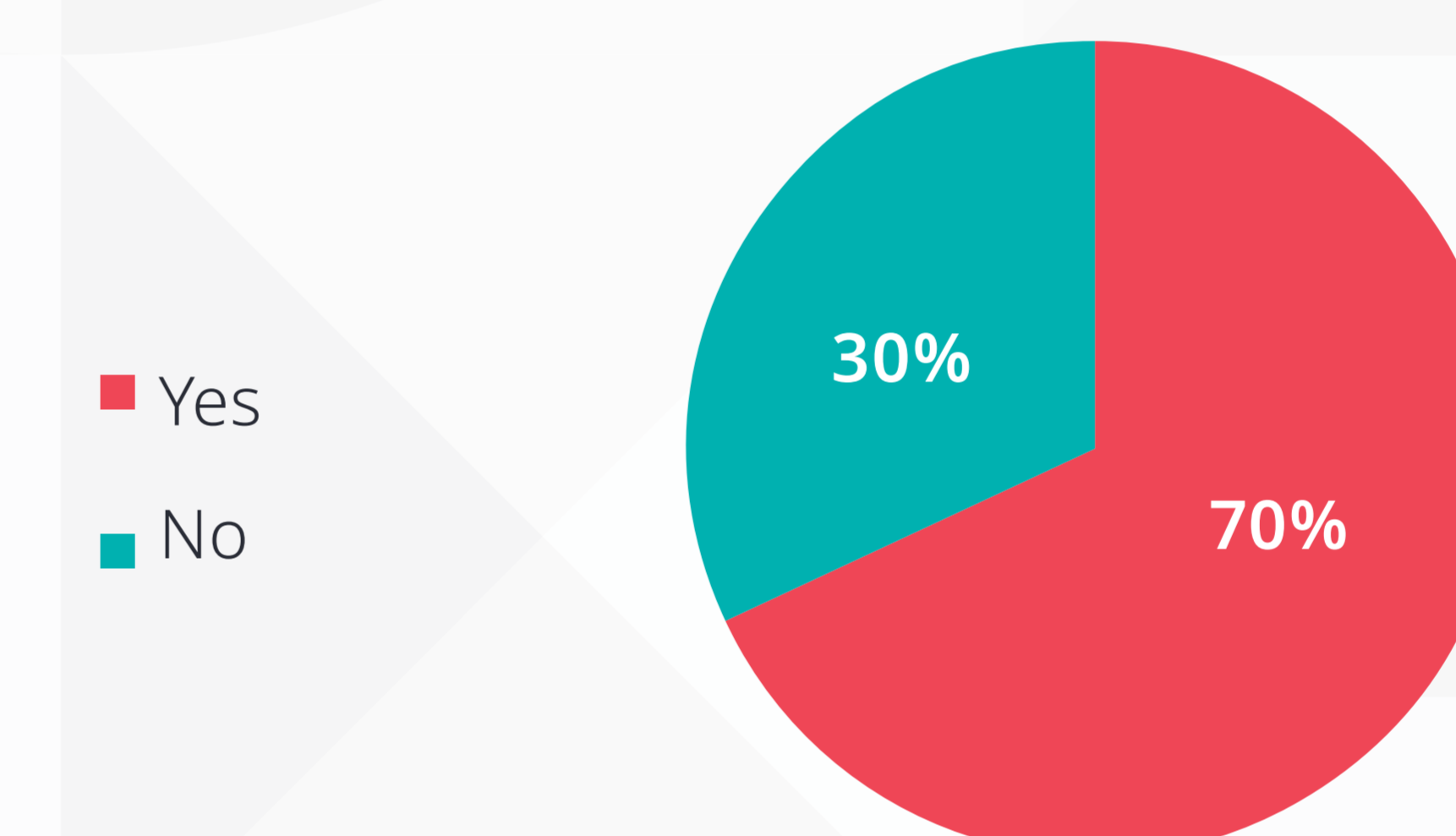
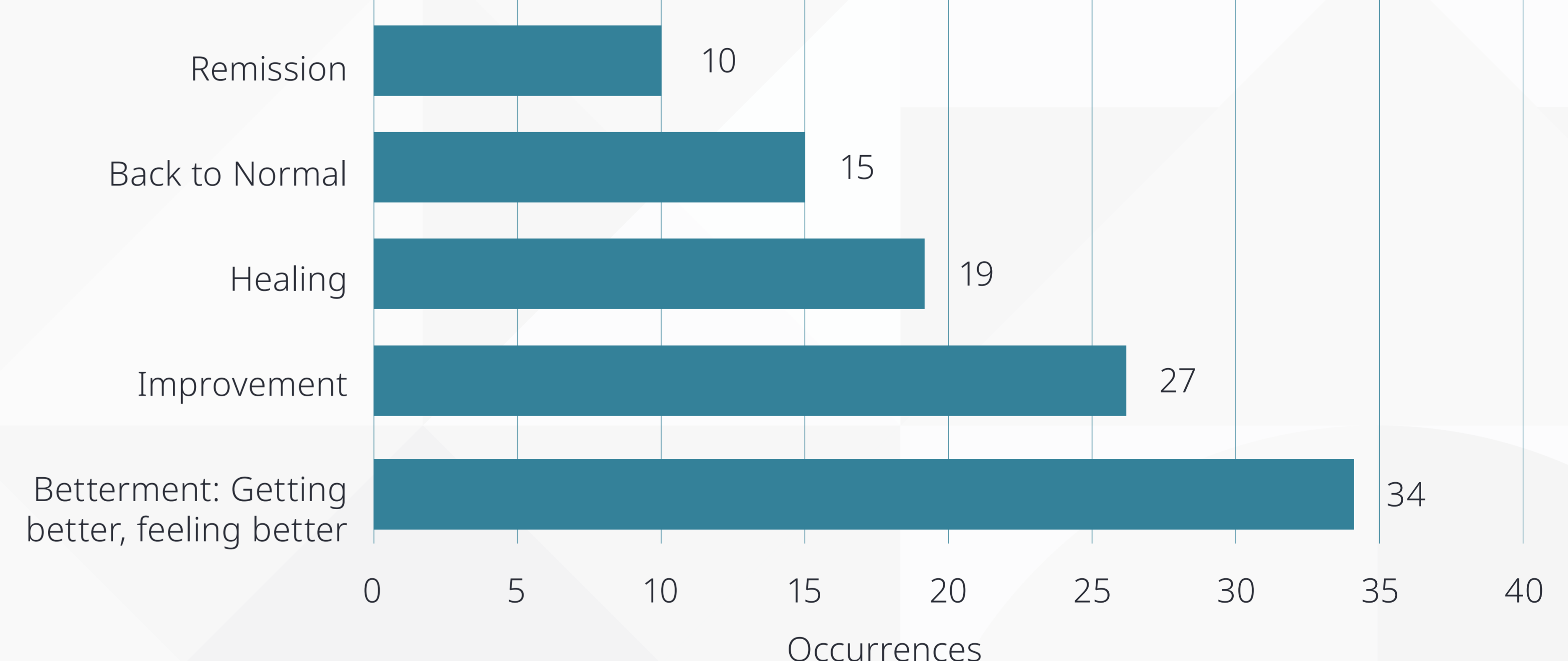


Figure 3: Most common alternative definitions of "recovery"



When defining "in recovery", nearly all subjects offered alternative terms that better support their own understanding of the term. The most common patient-offered replacements for "in recovery" include 'getting better/feeling better', 'improvement', 'healing', 'getting back to normal', and 'remission' (See Figure 3).

CONCLUSIONS

This study offers an understanding of how patients interpret "in recovery" in PROs text. Key takeaways to improve PRO use of this term include establishing a time period, specifying the role of symptoms, and taking into account whether the condition is chronic or curable. More generally, the results support the selection of more descriptive phrasing, which is furthermore endorsed by patients via pre-testing, in PROs. These results add to our body of work investigating ambiguous and difficult to translate PRO terminology, such as "disease activity", "bother", "self-conscious / embarrassed", and "depressed", and show that even common words and concepts require careful consideration when used in PROs to support clinical research.

References:

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