

Exploring regional variations in the cross-cultural, international implementation of the Patient Reported Outcomes Burdens and Experience (PROBE) study

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INTRODUCTION

- The Patient Reported Outcomes Burdens and Experience (PROBE) study has developed and validated the multilingual PROBE questionnaire for assessing patient reported outcomes in people living with hemophilia (PWH) and participants without bleeding disorders (NOBD).
- The translations of the PROBE questionnaire into local languages account for site specific language and cultural peculiarities in the management and life experience of hemophilia.

OBJECTIVE

- To explore regional variations in the international implementation of the PROBE questionnaire and examine the hypothesis that the PROBE score will not be confounded by cross-cultural aspects.

METHODS

- Data were collected from participants in four regions (Western Pacific, South America, North America and Europe).
- Participants were able to select from 23 localized language versions of the PROBE questionnaire based on their first language.
- We used analysis of variance methods and multivariable regression to determine the relative contribution of the variance explained by region controlling for hemophilia diagnosis, age group and level of education.
- We also explored interactions between regions and the other components.

RESULTS

Table 1. Variance component of health measures and PROBE score

Item	Variance component (%)				
	Region	Diagnosis	Age	Education	Individual
Mobility score	7.98	4.07	0.70	0.02	84.45
Pain Medication score	1.42	5.81	2.44	1.64	88.97
Acute pain occurrence score	0.44	12.06	0.98	0.14	86.96
Acute pain interference score	0.55	11.74	0.76	0.07	86.62
Chronic pain occurrence score	0.89	10.62	2.30	0.04	85.41
Chronic pain interference score	0.99	12.03	1.65	0.09	82.78
ADSL score	0.87	12.75	4.97	1.02	77.88
Absence from work/school score	0.64	4.12	0.76	2.71	89.72
Joint surgery score	2.08	5.60	4.88	2.08	84.99
Co-morbid disease score	0.85	3.78	2.42	0.83	91.24
PROBE score	0.26	22.42	3.42	0.34	70.74

Figure 1 PROBE score in participants with or without hemophilia, classified by regions

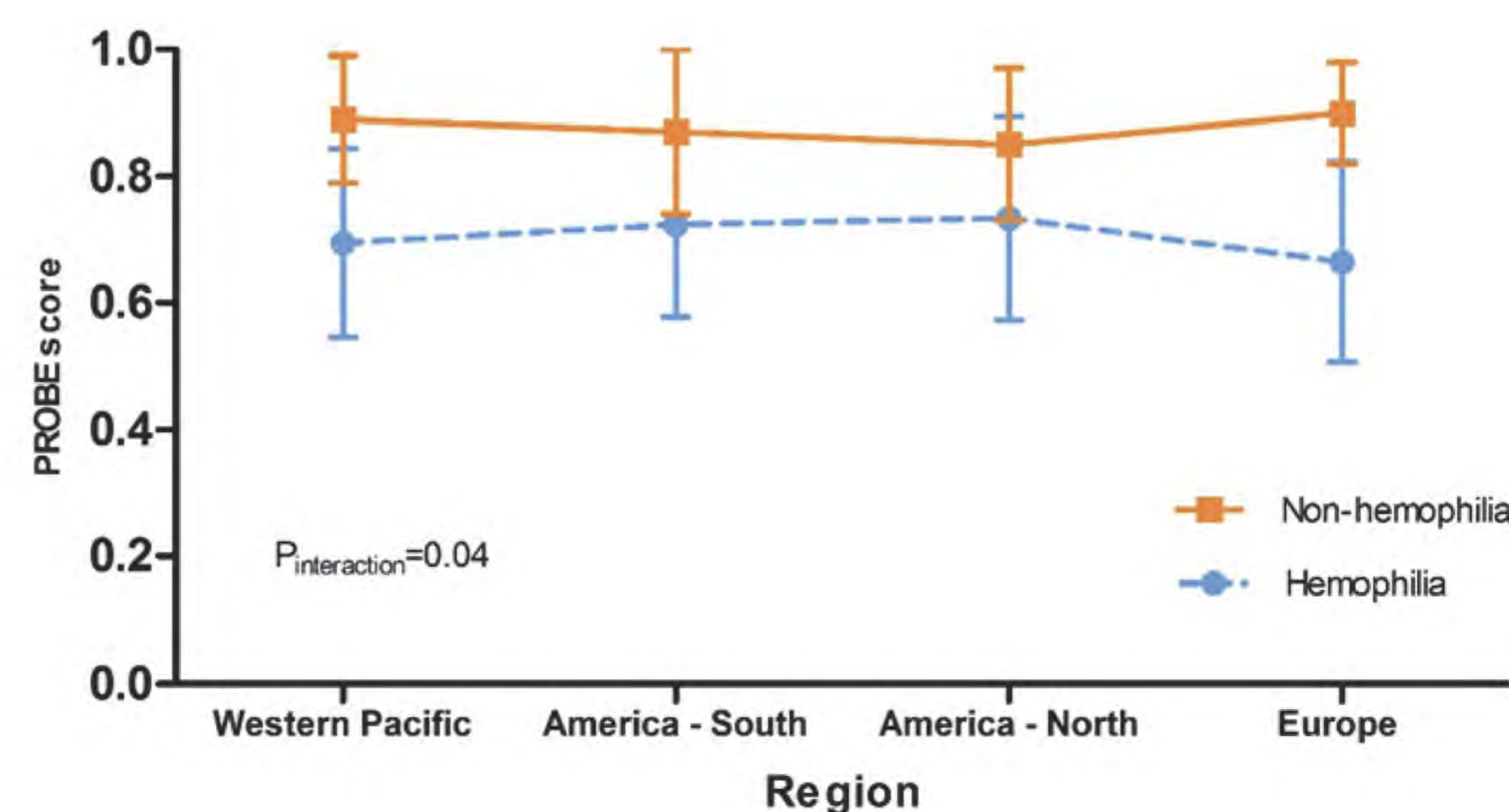
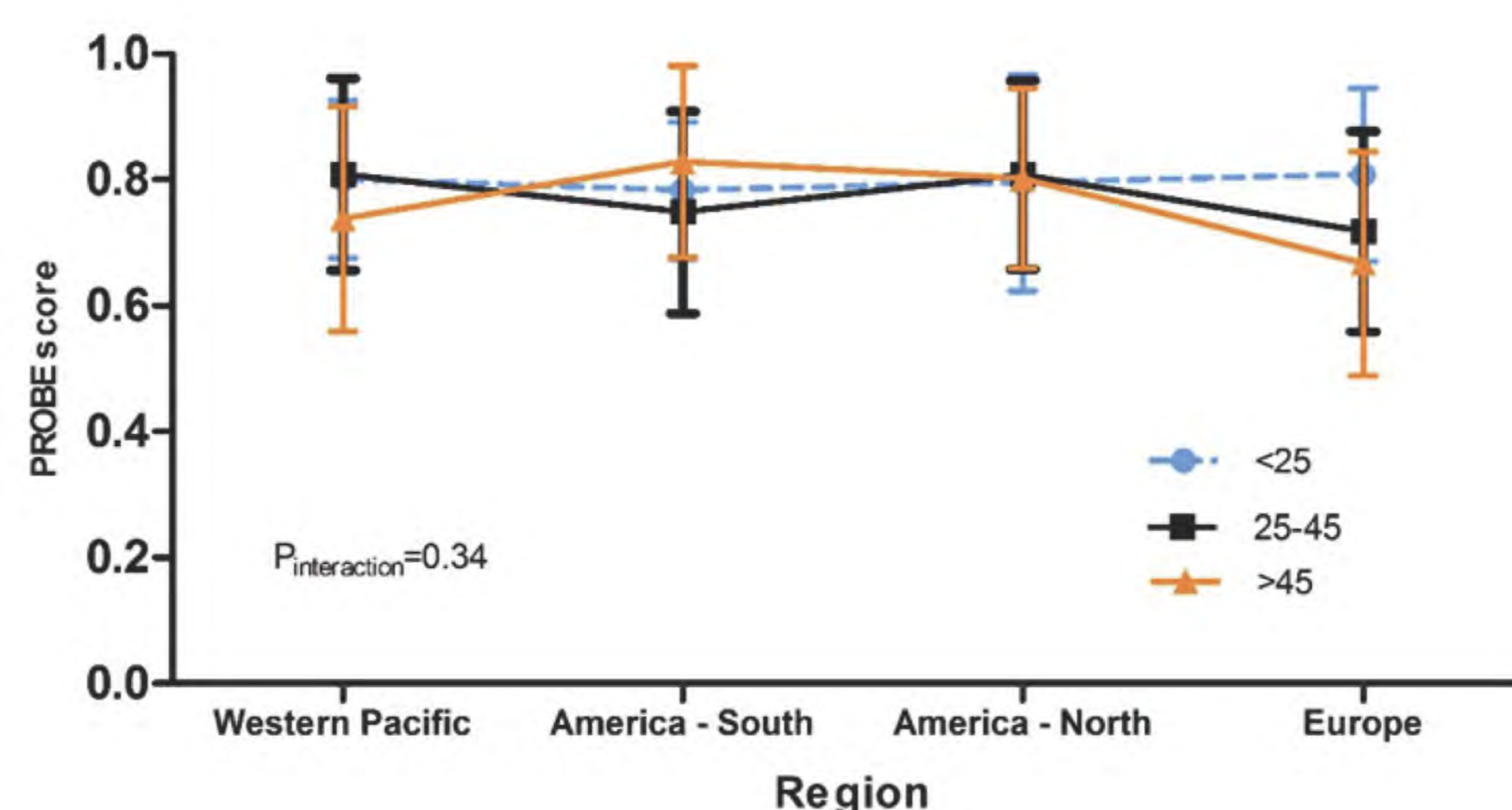


Figure 2 PROBE score in participants with different age groups, classified by regions



RESULTS

- We analyzed 862 questionnaires from 21 countries.
- Mean age of participants was 40.03 years (standard deviation 13.89).
- 65.20% were PWH, 34.80% NOBD. After adjusting for hemophilia diagnosis, age group and level of education, region contributed 0.44% to 7.98% of the variance component in sub-item scores and 0.26% in the PROBE score.
- Years of education contributed 0.34% in the PROBE score.
- Age and diagnosis (NOBD, mild, moderate, severe) contributed 3.42% and 22.42% of the PROBE score.
- 70.74% of the variance was explained by inter-individual variation.

CONCLUSIONS

- Variance partitioning for the PROBE score is similar to that for EQ5D.
- The results demonstrate that the PROBE questionnaire is valid to implement for assessing health status among PWH and participants without bleeding disorders across regions.

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