



# ASSESSMENT OF QUALITY OF LIFE OF PATIENTS IN KYRGYZSTAN USING THE PROBE TOOL

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**Introduction:** In resource constrained countries such as the Kyrgyz Republic, there is very limited availability of clotting factor concentrates which has a determinantal effect on the long-term health-related quality of life (HRQoL) of people with haemophilia (PWH).

**Methods:** HRQoL data was collected from PWH > age 10 using the PROBE questionnaire which also collects haemophilia related sequelae, socioeconomic variables and EQ-5D-5L. Descriptive methods were used to analyse the data set.





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PROBE Points of Interest		Haemophilia A and B
General	Age average (SD)	22.76 (8.25)
	Years of Education average (SD)	10.32 (3.25)
	Haemophilia A (%)	30 (81.08)
Severity	Severe (Factor level below 1%)	11 (29.73%)
	Moderate (Factor level 1–5%)	15 (40.54%)
	Mild (Factor level 5–40%)	1 (2.70%)
	I do not know	10 (27.02%)
Treatment	Access to some prophylaxis	7 (18.92%)
	Demand	22 (59.46%)
	No treatment available	6 (16.22%)
Acute and Chronic Pain	Acute pain	21 (56.76%)
	Chronic pain	28 (75.68%)
	Chronic pain in a target joint	17 (41.5%)
	Activity of Daily Living	26 (70.27%)
Employment/School Status	Unemployed/ long-term disability/ not a student	13 (35.14%)
	Student (full time or part-time)	11 (29.73%)
	Average of missed days of school or/and work	18.66 (days average)
Instrument for measuring General Health	EQ-5D-5L	0.73 (0.23)
Instrument for measuring general health and health with haemophilia	PROBE score	0.71 (0.13)
Joint Questions	Bleeding in last 2 weeks	14 (37.84%)
	Target Joints	25 (67.57%)
	Joint with a reduced Range of motion	31 (83.78)
	Life threatening bleed in the last 12 months	9 (24.32%)

## Results:

- 37 PWH with mean age (SD) of 22.76 (8.25) years
- Chronic pain reported in 75.68%
- Difficulty with activities daily living 70.27%
- Quality of Life (qol) scores were in line with other reported studies.
- Regular or Intermediate prophylaxis was available to almost 19% of all participants.
- Positive correlation in qol with increased access to prophylaxis.

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## Discussion/Conclusion:

This study was carried out in a cohort of PWH who did not have consistent access to factor concentrates. Among this cohort, the data demonstrate a significant impact on quality of life, joint health, employment, and chronic / acute pain. This lack of access to treatment has led to early disability, impacts on independence and work-life.

The introduction of low-dose prophylactic regimens has a demonstrated benefit for PWH. Implementation in the Kyrgyz Republic could significantly improve the health of future generations of PWH.

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