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# Summary data from the first collaboration of PROBE and Drustvo Hemofilikov Slovenije (DHS) – an ongoing quality of life study

A. KUCHER [1], E. CLEARFIELD [2], M. KAVČIČ [3], M. URBANČIČ [4], M. ŽIVIĆ KAVČIČ [5] and M. W. SKINNER [2,6]

1 Patient Outcome Research Group Ltd., USA
2 Institute for Policy Advancement, Ltd., USA
3 Alldea d.o.o., Slovenia
4 CLINUM, Minka Urbančič, s.p., Slovenia
5 Slovenian Haemophilia Society (Drustvo Hemofilikov Slovenije ), Slovenia
6 McMaster University, Hamilton, Ontario

Društvo hemofilikov Slovenije

PROBE®
Patient Reported Outcomes Burdens and Experiences Study

## INTRODUCTION

Drustvo Hemofilikov Slovenije (DHS) and the Patient Reported Outcomes Burdens and Experiences (PROBE) study have initiated a collaboration to discover the quality of life (QoL) for people with hemophilia (PWH) in Slovenia.

## METHOD

Data was collected using PROBE's web-based questionnaire.

- PROBE collects data in four categories:
  - personal demographics
  - general health problems
  - hemophilia-specific health problems
  - Euro-QoL 5 dimensions 5 levels (EQ-5D-5L).
- Descriptive statistics are provided (N,%).

## CONCLUSIONS

Collaboration between DHS and PROBE launched recently, with a goal to administer PROBE to at least half of the severe and moderate population of PWH in Slovenia. These data from the first set of participants shows the impact and importance of QoL data collection for the patient organization. PROBE can be used to measure access to the treatment, one of the most valuable indications of positive impact on QoL for PWH. PROBE also measures other key outcomes affecting QoL for PWH. Data collection is ongoing, and further analyses will be completed to understand the impact of living with hemophilia in Slovenia.

## ACKNOWLEDGEMENT

The Slovenian Haemophilia Society (Drustvo Hemofilikov Slovenije ) wishes to thank those living with hemophilia who participated in this study and McMaster University for their support in hosting and securely storing study data.

PROBE data is securely stored and monitored at McMaster University, Canada.

## RESULTS

Twenty-four PWH A and B participated (Table 1); 91.7% (n=22) were PWHA. The average age (SD) was 44.3 (18.4) years. Most participants had severe hemophilia 62.5% (n=15), moderate and mild hemophilia were reported by 16.7% (n=4) and 20.8% (n=5), respectively. Nineteen (79.2%) reported access to prophylaxis treatment, and two (8.3%) reported using on-demand treatment. One person reported that treatment was not available. In the family section, 58.3% (n=14) reported being married/in a long-term relationship and 54.2% (n=13) have children. Frequency of use of pain medication was low: 45.8% (n=11) reported using it "rarely" (1-5% of the time), and 25% (n=6) selected that they did not use any pain medication. The presence of acute pain and chronic pain was reported by 50% (n=12) and 70.8% (n=17), respectively. Fifty percent (n=12) indicated their chronic pain is due to target joint/s. Seventeen people (70.8%) indicated they had a target joint. PROBE and EQ-5D-5L scores range from 0 to 1, with a score closer to 1 meaning better QoL. Mean (SD) scores for PROBE and EQ-5D-5L were 0.803 (0.16) and 0.841 (0.14), respectively.

Summary data for people with hemophilia A and B who completed PROBE questionnaire. Table 1.

| Hemophilia A and B N=24 | |
|---|---|
| General | N (%) |
| Age average (SD) | 44.3 (18.4) |
| Years of Education average (SD) | 12.8 (4.5) |
| Hemophilia A (%) | 22 (91.7%) |
| Severity | |
| Mild (Factor level 5–40%) | 5 (20.8%) |
| Moderate (Factor level 1–5%) | 4 (16.7%) |
| Severe (Factor level below 1%) | 15 (62.5%) |
| Treatment | |
| Access to prophylaxis | 19 (79.2%) |
| Demand | 2 (8.3%) |
| No treatment available | 1 (4.2%) |
| Family | |
| Married | 14 (58.3%) |
| Children | 13 (54.2%) |
| Pain med Frequency | |
| Never (0% of the time) | 6 (25%) |
| Rarely (1–5% of the time) | 11 (45.8%) |
| Occasionally (6–25% of the time) | 2 (8.3%) |
| Sometimes (26%–50% of the time) | 0 |
| Frequently (51%–75% of the time) | 2 (8.3%) |
| All the time (100%) | 1 (4.2%) |
| Health Related | |
| Used a mobility device in the past 12 months | 6 (25%) |
| Acute pain | 12 (50%) |
| Chronic pain | 17 (70.8%) |
| Chronic pain in a target joint | 12 (50%) |
| Activities of Daily Life (ADL) affected | 9 (37.5%) |
| Joint Surgery | 17 (70.8%) |
| Employment and Education Status | |
| Unemployed/ long-term disability | 4 (16.7%) |
| Working full-time / working part-time | 11 (45.8%) |
| Retired | 3 (12.5%) |
| Other Employment status | 4 (16.7%) |
| Student (full-time or part-time) | 3 (12.5%) |
| Average of missed days of school or/and work | 9.125 |
| Scores | |
| EQ5D | 0.841 (0.14) |
| PROBE | 0.803 (0.16) |
| Hemophilia Related | |
| Bleeding in the past 2 weeks | 4 (16.7%) |
| Target Joints | 17 (70.8%) |
| Joint with a reduced Range of motion | 6 (25%) |
| Life-threatening bleed in the past12 months | 5 (20.8%) |

## CONTACT INFORMATION

**Drustvo Hemofilikov Slovenije**

www.DHS.si

info@dhs.si

*The main goal of the association is to live with hemophilia and other congenital disorders of blood clotting (lack of clotting factors and disorders of platelet function). In line with the mission of the World Federation of Haemophilia, it shall contribute to integrated care in partnership with experts on the basis of the principle of solidarity through initiative and organisational activity. This raises the quality of life despite an incurable disease by respecting the guidelines of health experts for these rare diseases.*

**PROBE**

www.PROBEStudy.org

info@probestudy.org

*At our website you can learn about PROBE's worldwide reach, access our e-platform, find answers to frequently asked questions, and click through our published research to see the types of analyses that can be done using PROBE data.*