

## Background & Objective

- National-level patient-reported outcomes for people with hemophilia in Kosovo remain limited.
- PROBE captures health related quality of life, treatment patterns, pain, function, health status, and day-to-day burden.
- Objective: characterize the Kosovo cohort and compare outcomes across Severe, Moderate/Mild, and local controls with no bleeding disorder (PwNBD).

## Methods

- Cross-sectional analysis of participants in Kosovo who completed PROBE during the WFH twinning program between NBDF and KHF.
- Formal cooperation involved KHF, NBDF, WFH, and the Ministry of Health of Kosovo.
- A February 2024 memorandum of understanding executed by WFH, KHF and the Kosovo Ministry of Health include PROBE data collection as part of the formal collaboration.
- Data collection window: April 2023 to May 2024 during two national workshops and recruitment via the KHF database.
- Outcomes included treatment regimen, acute and chronic pain, missed work/school, EQ-5D index, and PROBE total score.

## Cohort Snapshot

<b>n=6</b> Severe hemophilia	<b>n=13</b> Moderate / Mild hemophilia	<b>n=12</b> PwNBD controls
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Mean age (years): 29.5 • 29.5 • 36.3 respectively  
Mean years of education: 12.2 • 12.6 • 14.9 respectively

33 participants were included in the initial pilot collection, enabling descriptive comparison across disease severity and a local control group.

## Why This Matters

- Patient-reported outcomes provide an evidence base that complements clinical information.
- The Kosovo pilot highlights burden beyond bleeds alone, including pain, function, and impact on education/work.
- These data can inform health policy, service planning, and advocacy for improved hemophilia care.

## Study design at a glance

- PROBE + EQ-5D-5L
- Descriptive comparison
- Severe vs Moderate/Mild vs PwNBD
- Pilot dataset to guide longitudinal monitoring

**Better visibility of burden**  
→ **stronger national evidence**

## Selected data highlights

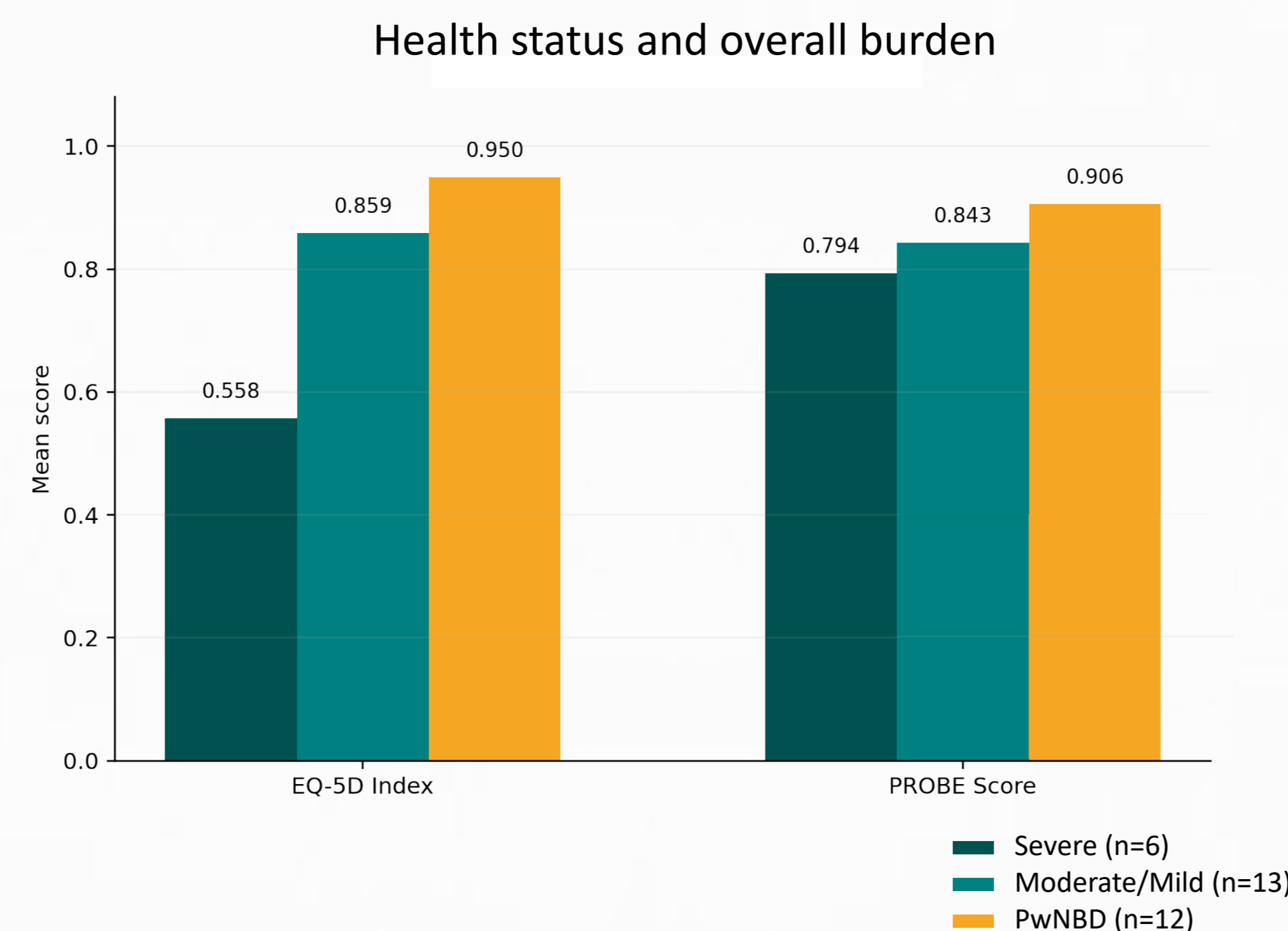
- EQ-5D: 0.558 vs 0.859 vs 0.950
- PROBE score: 0.794 vs 0.843 vs 0.906
- Missed days: 25.7 vs 10.9 vs 7.4
- Severe prophylaxis rate: 33.3%

We would like to sincerely thank the National Bleeding Disorder Foundation and the Kosovo Hemophilia Foundation for their valuable participation in the PROBE Study and for their support with data collection.

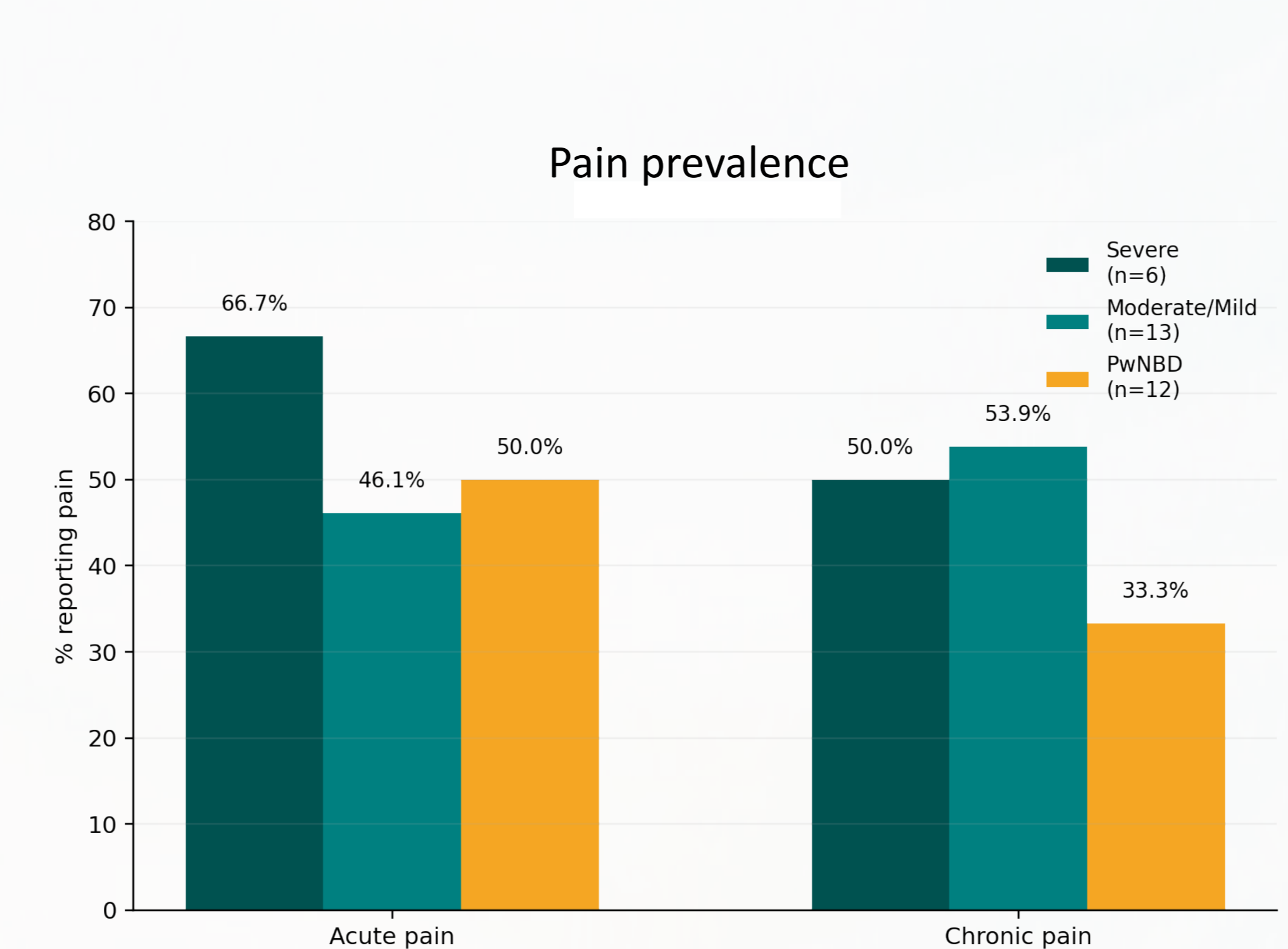
PROBE team Contact Information: [www.PROBEstudy.org](http://www.PROBEstudy.org) or [info@probestudy.org](mailto:info@probestudy.org)

Abbreviations: PROBE = Patient-Reported Outcomes, Burdens and Experiences; PWH = people with hemophilia; PwNBD = people with no bleeding disorder; ADL = activities of daily living; KHF = Kosovo Hemophilia Foundation; WFH = World Federation of Hemophilia; NBDF = National Bleeding Disorder Foundation.

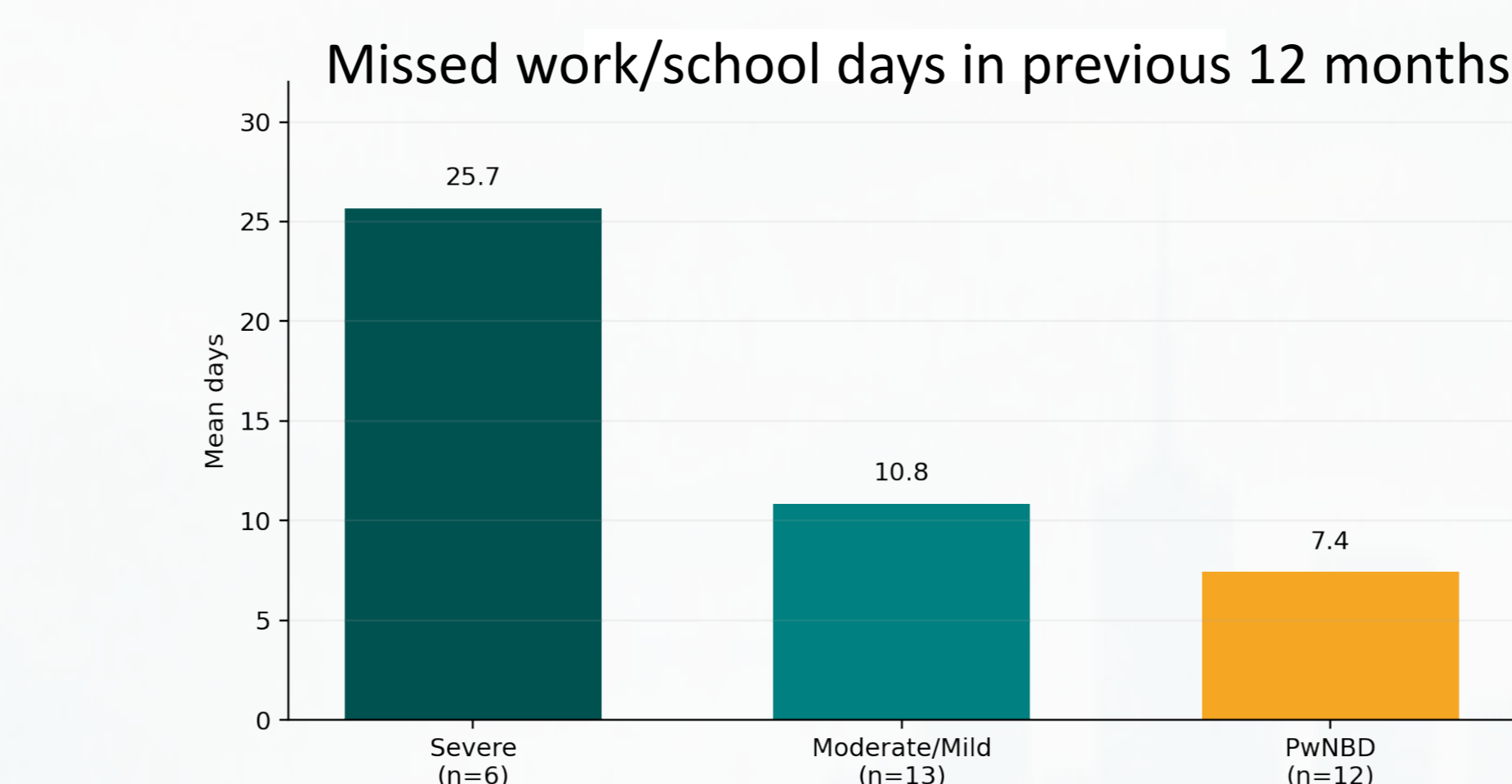
## Health Status & Overall Burden



## Pain Burden



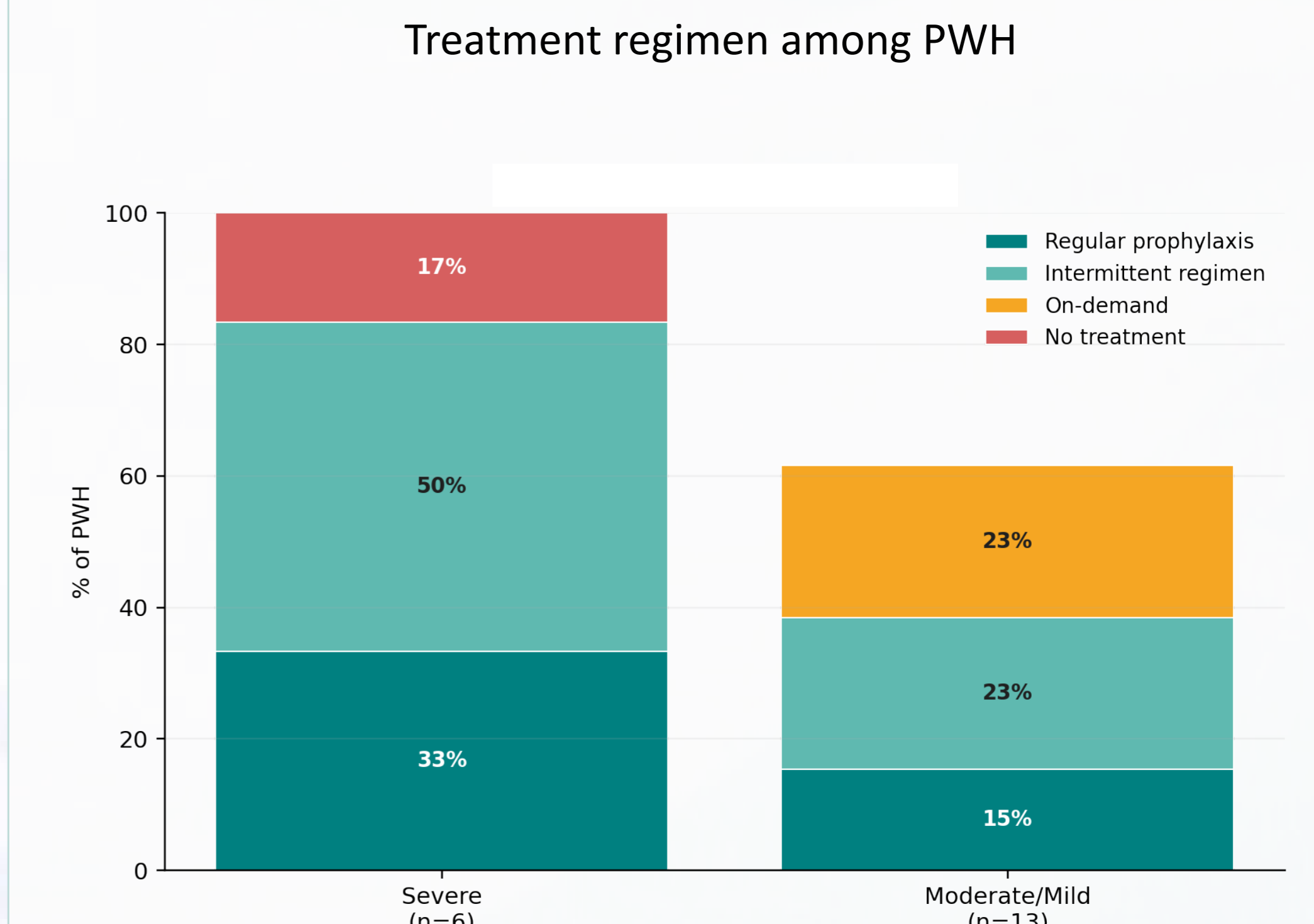
## Functional Impact



## Selected functional indicators

- ADL affected: 66.7% (Severe), 53.9% (Moderate/Mild), 16.7% (PwNBD)
- Mean number of ADLs affected: 2.17 (Severe), 1.77 (Moderate/Mild), and 0.25 (PwNBD)
- Target/problem joints: 83.3% (Severe) and 84.6% (Moderate/Mild)

## Treatment Patterns Among PWH



## Key Findings

- Both hemophilia groups reported lower EQ-5D and PROBE than PwNBD. A lower score means a lower quality of life.
- The Severe cohort showed the lowest mean EQ-5D (0.558) and the highest average missed work/school burden (25.7 days).
- Acute pain was especially prominent in Severe hemophilia, while chronic pain remained common across hemophilia groups.
- Only one-third of Severe participants reported regular prophylaxis; some reported no treatment availability.

## Clinical signal

The pattern across pain, activity limitation, and missed school/work suggests a broader functional burden that is not fully explained by diagnosis alone and may be amenable to improved access to prophylaxis and joint care.

## Implications & Conclusions

- Findings highlight persistent unmet needs in access to on-demand, regular prophylaxis, pain management, and physio joint health support. The pilot exercise demonstrated feasibility and provided initial insights supporting an on-going need for care development in Kosovo.
- PROBE provides a patient-centered framework to monitor burden and benchmark health status in Kosovo
- Although approximately 20% of the known PWH in Kosovo participated, the sample size is small. Ongoing data collection will support longitudinal evaluation to guide national health policy for PWH.

## Take-home message

**In Kosovo, severe hemophilia was associated with lower health status, greater burden, and more disruption to daily life than moderate/mild disease — and both hemophilia groups fared worse than those living without a bleeding disorder.**