

National Member Organization's PROBE Data Dashboard Update – Adding A Pain Dashboard Page for Better Understanding of the Pain Impact in People with Hemophilia.

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INTRODUCTION

The Patient Reported Outcomes, Burdens and Experience (PROBE) study has been implemented in 105+ countries and translated into 50+ languages. How does the study benefit national member organizations (NMO)? The PROBE team has developed an interactive dashboard utilizing data from the pain elements of the PROBE questionnaire, a validated hemophilia-specific quality of life instrument. This dashboard is provided upon request to participating NMOs of the World Federation of Hemophilia for their use and analysis of their country's data. The dashboard includes options to aggregate data, generate graphs, and utilize filters to support and specific data analyses.

METHOD

Development of the PROBE NMO Dashboard started in 2017.

The dashboard was developed using Power BI, Microsoft software for data visualization. Since then, the dashboard has been modified to provide an enhanced data presentation for NMOs with health policy decision makers or to test and analyze hypotheses.

The PROBE questionnaire asks participants to report on 5 aspects of pain during the past 12 months:

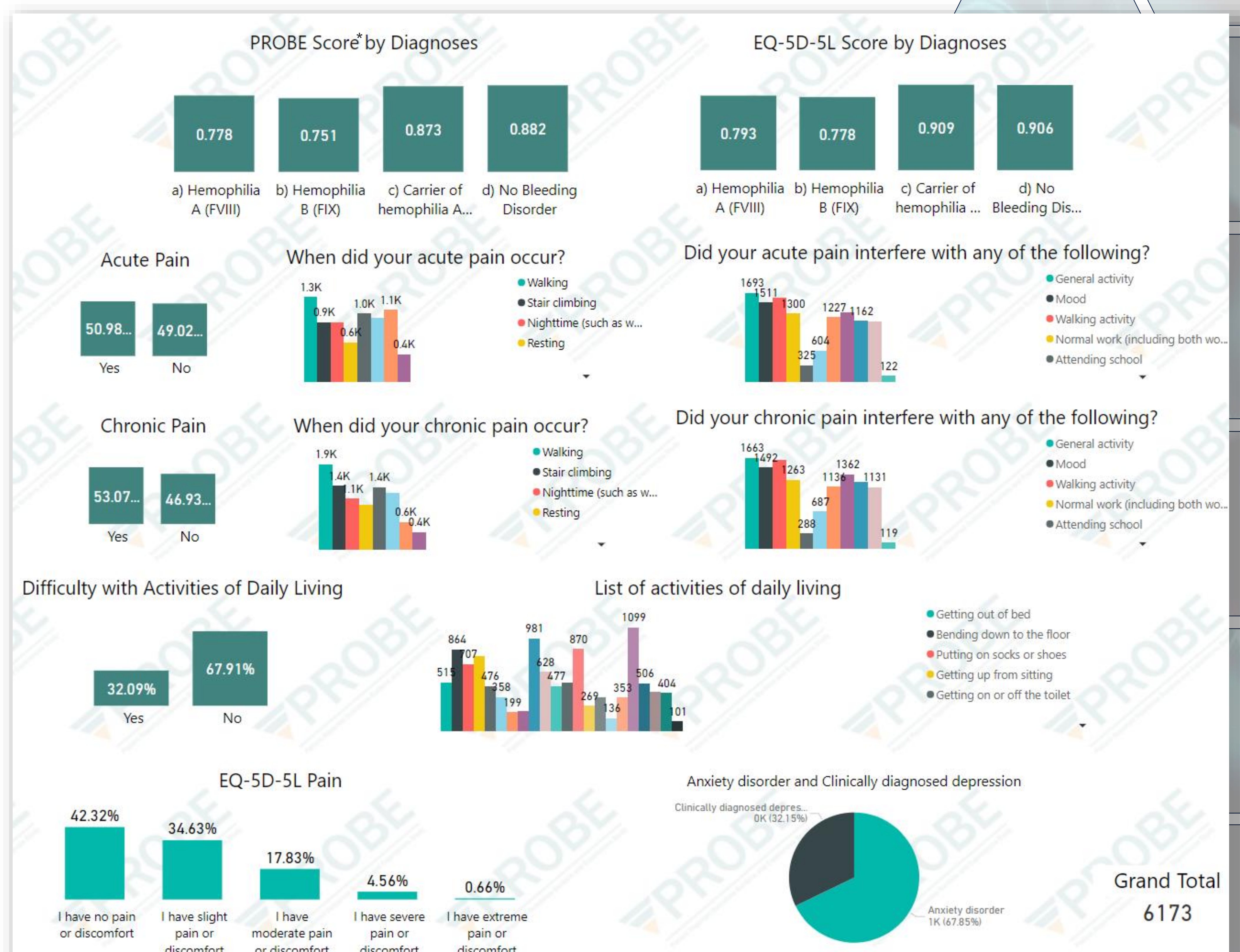
- Any occurrence of acute and/or chronic pain
 - “Acute pain” is defined as pain that arises in response to an event (like an injury or bleeding episode)
 - “Chronic pain” is defined as pain from a persistent cause; it can vary in frequency and intensity (like back pain, pain from sore joints, or arthropathy). “Chronic pain” does not include “acute pain”
- Pain occurrence during 8 activities (walking, stair climbing, nighttime, resting, weight bearing, playing, after falling/trauma, other)
- Pain interference in 11 aspects of life (general activity, mood, walking ability, normal work, attending school, relations with others, sleep, enjoyment of life, playing/participating in sports/exercising, lifting, other)
- Use of any pain medication and frequency of pain medication use (frequency not presented)
- Chronic pain in target joints (not presented)

RESULTS

The importance of detailed PROBE responses regarding pain has been discussed among the PROBE Investigator team and approved for modification. The newest upgrade to the dashboard is a specific Pain Page that covers detailed data about acute and chronic pain interference and occurrences, activities of daily living, the EQ-5D-5L pain dimension, PROBE anxiety and depression items, PROBE score and EQ-5D-5L score.

CONCLUSIONS

The pain page on the PROBE dashboard demonstrates that a person's experiences with pain are highly important for reporting on quality of life for people with hemophilia. Having the ability to compare both a control group and hemophilia group with pain occurrences and interferences can support claims of better or worse quality of life that could be addressed through healthcare management or and improved access to treatment. Analyzing PROBE and EQ-5D-5L together demonstrates the importance of using both generic and disease specific quality of life instruments. The pain dashboard page will be a valuable asset for NMOs for pain reports and management for people with hemophilia.



*The total PROBE score ranges from 0 to 1 and the maximum score of 1 indicates the best HRQoL

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DEMO

Scan the QR code to view an interactive sample of the new PAIN PAGE within the PROBE Dashboard.

Please note, all data presented is for demonstration purposes only.

