

# Incorporating Patient Reported Outcomes into Clinical Practice: a 360-degree Clinical Evaluation for Better Care and Treatment of People with Hemophilia through myWBDR and myPROBE

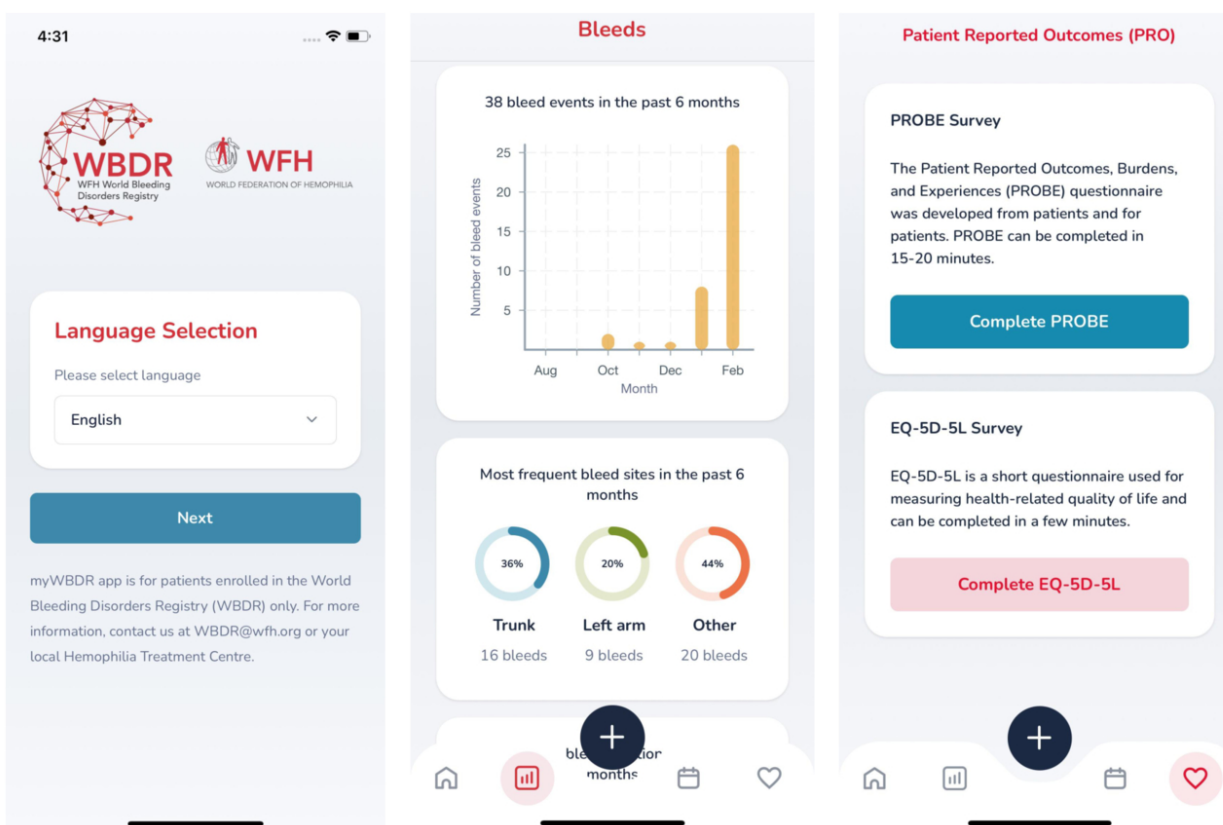
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## INTRODUCTION

The World Federation of Hemophilia (WFH) World Bleeding Disorders Registry (WBDR) is designed **to fill gaps in hemophilia care and knowledge that exist globally**. The WBDR is a tool for clinicians to collect real world data on patient clinical care and quality of life, and a tool to empower people with hemophilia (PWH) to manage their own care and treatment. **The WFH is introducing myWBDR – a mobile application for PWH participating in the WBDR through the participating hemophilia treatment centers.**



## METHODS

myWBDR is designed to **track bleeds, associated pain, treatments, and health status using EQ-5D-5L** and the **Patient Reported Outcomes, Burdens, and Experiences (PROBE)** questionnaires. Initially, myWBDR will be available in English, French, Hindi, Russian, Spanish, Thai, and Vietnamese.

Hemophilia Treatment	PROBE: Burden of Disease	Quality of Life
myWBDR	myPROBE	EQ-5D-5L
<b>Bleed history:</b> location of bleed, frequency, access to treatment at time of bleed	<b>Pain:</b> chronic/acute, interference, occurrence	<b>Mobility</b>
<b>Pain level:</b> pain associated with a bleed event.	<b>Independence:</b> limitations, impact on activities of daily living	<b>Self-care</b>
<b>Treatment record:</b> infusion log, dose, frequency, reason for treatment, location of treatment received.	<b>Education:</b> attainment, attendance	<b>Usual Activities</b>
	<b>Employment:</b> duration, underemployment, attendance	<b>Pain / Discomfort</b>
	<b>Family Life:</b> marriage, children	<b>Anxiety / Depression</b>
	<b>Mobility:</b> assistance required, impairment	<b>VAS</b> (visual analog scale)

## RESULTS

myWBDR had undergone field testing in non-WBDR PWH. We now initiate a **testing cohort of PWH within the WBDR**. Implementation is regional, starting with 5 countries (2 regions) in Q3 2021. **myWBDR is a simple tool**, allowing users to record accurate bleeds and treatment in **under 1 minute**. The **inclusion of the EQ-5D-5L and PROBE questionnaires**, both available in a large number of languages, will allow users to track changes in their health status over time. Both myWBDR and myPROBE include **an off-line feature** so data can be entered at anytime and offer **simple data visualization** on bleeds (number, location), level of pain and health-status.

## CONCLUSION

**Integration of Patient Reported Outcomes via the myWBDR** will allow PWH to play an **active role in their care and treatment**. **With the 360-degree data**, researchers can better understand hemophilia and improve quality of care and treatment for PWH around the world. A data dashboard for PWH to visualize and compare their personal data is in development.

## INTRODUCING myWBDR Video (click on image below)

