

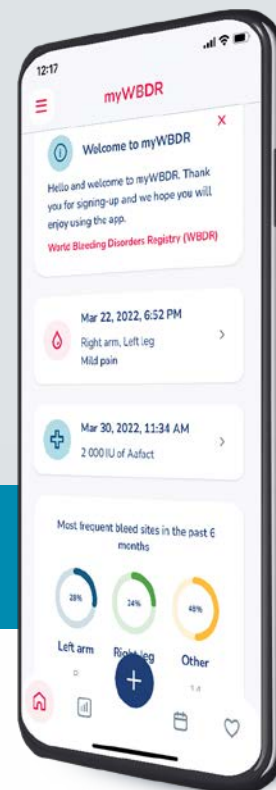
Introducing the myWBDR mobile app

A tool for accurately and securely recording bleeds and treatments, and monitoring health status for WBDR participants



myWBDR

WFH WORLD BLEEDING
DISORDERS REGISTRY



GET INVOLVED WITH YOUR TREATMENT

What is the World Bleeding Disorders Registry (WBDR)?

The WBDR is an online web-based data entry system that allows hemophilia treatment centres (HTCs) around the world to collect uniform and standardized patient data to guide clinical practice.

To learn more about the WBDR, visit wfh.org/data-collection/#wbdr

What is myWBDR?

myWBDR is a mobile application designed for WBDR patients diagnosed with hemophilia and/or von Willebrand disease (VWD). With a primary objective of empowering patients, myWBDR offers users a user-friendly platform to effortlessly track and monitor bleeding episodes, pain levels, treatments, and overall health status using EQ-5D-5L and PROBE questionnaires. It is available in the following languages: Arabic, English, French, Hindi, Portuguese, Russian, Spanish, Thai and Vietnamese.

Who can use myWBDR?

Patients diagnosed with hemophilia and/or VWD who are enrolled in the WBDR through their hemophilia treatment centres (HTCs).

What information can be recorded using myWBDR?

- Bleed information (number of bleeds, date, location)
- Level of pain
- Treatments
- Health status using EQ-5D-5L and Patient Reported Outcomes, Burdens, and Experiences (PROBE) questionnaire (for hemophilia patients)

EQ-5D-5L is an easy-to-complete self-assessment questionnaire. It is designed to measure health-related quality of life in five dimensions, including mobility, self-care, usual activities, pain/discomfort, and anxiety/depression.

PROBE is a long-term study aimed at measuring health status and quality of life outcomes for patients with hemophilia A and B. The main goal of the PROBE study is to provide data that can be used to advocate for better care and treatment.



How do I sign-up for myWBDR?

1 THROUGH YOUR HTC CLINICIAN

You can request your clinician to sign you up directly in the WBDR (recommended)

2 THROUGH YOUR MOBILE DEVICE

- A** Download the myWBDR app from the Apple Store or from the Google Play Store
- B** Select your preferred language and click "Sign-up"
- C** Complete the information on the "Sign-Up" page
- D** Click on "Find Me". This is to identify you as a WBDR patient and to associate your WBDR account with the myWBDR app.
- E** If the myWBDR app can associate you with the WBDR account, you will be prompted to create username and password. If the myWBDR app cannot associate you with the WBDR account, please contact your HTC to sign up.
- F** View and accept the terms of use and the privacy policy
- G** Click on "Sign-up" and you will receive an email to complete the process



What are the benefits of using myWBDR?

- ✓ **ELIMINATES** the need for paper diaries
- ✓ **FACILITATES** quick bleed and treatment data entry (less than 60 seconds)
- ✓ **RECORDS AND TRACKS** changes in health status through EQ-5D-5L and PROBE questionnaires
- ✓ **TRANSMITS** data immediately to the WBDR when connected to the internet so clinicians can see the patient data in real-time
- ✓ **EMPOWERS** patients to play an active role in helping researchers better understand bleeding disorders
- ✓ **CREATES** simple data visualization of bleeds (number, location) and the level of pain associated with those bleed events
- ✓ **WORKS** offline to allow data to be recorded without an internet connection

If you have questions or would like more information about myWBDR, contact us at myWBDR@wfh.org

Is using myWBDR mandatory?

No, using myWBDR is optional.

When should myWBDR be used?

We recommend that myWBDR be used whenever you have a bleed and/or receive treatment.

What about the privacy of participants?

All information entered in the WBDR and in myWBDR is anonymous and confidential. Patient names or other identifying information are not stored.

Who has access to your data?

Only your HTC care team and the WFH have access to WBDR data.

The World Bleeding Disorders Registry is supported by funding from our visionary partners: Sobi and Takeda; and our collaborating partners: Bayer, CSL Behring, F. Hoffman-La Roche, Grifols, Novo Nordisk, Pfizer, and Sanofi.

