

WBDR - Quick Reference Guide



To access the WBDR, go to: <https://wbdr.realq.se/login/>

Patient Registration

Registering a new patient

- Click on the Register **New Patient / Find Patient** tab in the menu bar
- At the bottom of the page, select patient's bleeding disorder diagnosis and enter required information
- Once completed, click on "Register Patient"

Searching for an existing patient

- Click on the Register **New Patient / Find Patient** tab in the menu bar
- Search for the patient by entering the Patient WBDR ID or date of birth
- Select the patient in the results grid by clicking on the Patient ID number

Adding baseline data

Baseline data captures the patient demographics, diagnosis and medical history. This page is completed once per patient and the data does not change over time.

If a patient was diagnosed with **Hemophilia & VWD**, both Baseline Data pages must be completed.

- After you have registered a new patient, you will be automatically directed to the Baseline Data page specific to the bleeding disorder diagnosis selected
- The Baseline Data page can also be found by clicking on the **Patient Data** tab in the menu bar, and then clicking on the **Baseline Data Hemophilia** or **Baseline Data VWD** sub-tab
- Complete this page and press "Save/Next"

Adding a baseline visit

Baseline visit is the patient's first visit after their registration in the WBDR. It captures data on all events the patient has experienced during the 6-month period prior to their entry into WBDR.

This page is completed once per patient and is the same regardless of the bleeding disorder diagnosis.

- After you have completed the Baseline Data page, you will be automatically directed to the Baseline Visit page
- The Baseline Visit page can also be found by clicking on the **Patient Data** tab in the menu bar and then clicking on the **Baseline Visit** sub-tab
- Complete the page, including all applicable modules, and press "Save"

Adding a follow up visit

A follow up visit is completed every time a patient visits the clinic, after their baseline visit. It captures data on all events the patient has experienced since their last visit.

This page is the same regardless of the bleeding disorder diagnosis.

- Search for and select your patient
- You will be automatically directed to Follow Up Visit page
- Complete the page, including all applicable modules, and press "Save"

Patient Transfer / Discharge

Patient Transfer

If a patient starts receiving care at a different HTC registered in the WBDR, a Patient Transfer can be made.

- Search for and select your patient
- The Patient Discharge / Transfer page can be found by clicking on the **Patient Data** tab in the menu bar, and then clicking on the **Patient Discharge / Transfer** sub-tab
- For a transfer, choose the HTC you want to transfer the patient to in the drop down list at the bottom of the window then click on "Transfer"

Patient Discharge

If a patient withdraws from the WBDR for any reason, a Patient Discharge must be recorded.

- Search for and select your patient
- The Patient Discharge / Transfer page can be found by clicking on the **Patient Data** tab in the menu bar, and then clicking on the **Patient Discharge / Transfer** sub-tab
- For a discharge, complete this page by adding the date of discharge and the reason for discharge and press "Save"

Patient Mortality

Following the death of a patient enrolled in the WBDR, a Patient Mortality must be recorded.

- Search for and select your patient
- the Patient Mortality page can be found by clicking on the **Patient Data** tab in the menu bar, and then clicking on **the Patient - Mortality** sub-tab
- Complete this page and press "Save"

Entering data in different Modules

All Modules can be completed at the Baseline Visit and all Follow Up Visit pages.

At **Baseline Visit and Follow Up visits**: If you have selected YES for the following questions, please enter further information in each module accordingly:

- 'Inhibitor assessment in the past 6 months / since last clinic visit'
- 'Admission to hospital in the past 6 months / since last clinic visit'
- 'Treatment received in the past 6 months / since last visit'
- 'Did the patient experience any adverse events in the past 6 months / since last clinic visit'
- 'In the past / since last clinic visit', has the patient given birth, had a pregnancy termination or miscarriage?'

To add information in each module:

- Scroll down to related module and press new at the bottom of the table.
- Enter all required data in each module (see full details on the right).
- Press Save/New, to save your data and add another entry.
- Press Save/Close to save your data and close the module.
- Press Delete, to delete the data you entered and not save it.
- Press Close, to close the module without saving the data.

Data Entry Tips

- Height values must be in (cm) and weight values must be in (Kg)
- While entering data, if the exact date is unknown, enter January 1st of the estimated year
- An outline of all patient data can be found in the patient summary sub-tab
- All fields marked with an (*) are required fields
- There's no need to re-enter a chronic condition, in the comorbidities sections, if it was entered previously, eg diabetes

myWBDR - A mobile application for PWH

myWBDR is a digital tool to track bleeds and treatments for PWH. All patients registered in the WBDR are eligible.

HCPs can initiate the sign-up process through the WBDR:

- Search for and select your patient
- Go to Patient-reported outcomes under the Patient Data tab
- Select myWBDR signup page sub-menu
- Enter patient's email, select preferred language and click sign-up



Inhibitor Assessments Module

Complete the fields in the module

- Titre (BU/ml) value is only required for Bethesda and Nijmegen-Bethesda.

Hospital Admissions Module

Complete the fields in the module

- If the hospitalization was ongoing at the time of the clinic visit, the number of days hospitalized can be left blank. This can be completed when the patient is discharged.

Treatments Module

Complete the fields in the module

- If the treatment is on-going during their Follow Up visit, "reason for stopping treatment" and "end date" should be left blank.
- If a treatment is changed or stopped, the current entry must be completed by entering an "end date" and a "reason for stopping treatment".
- The new regimen is entered as a new entry.

Note

- The reason for stopping treatment should be consistent with the indication of treatment. (ex: Indication = On demand; reason for stopping treatment = On demand treatment complete)
- Only one treatment can be on-going. All other treatments entries should have an end date.
- For Emicizumab-specific instructions, please refer to the WBDR Emicizumab Guide.

Adverse Events Module

Complete the fields in the module

- If the adverse event was not resolved during the Follow Up Period, leave date of resolution blank. It can be completed when the adverse event is resolved.

Pregnancy Module

This module is unique to female patients

- Complete the fields in the module only if the patients have had a pregnancy outcome.

To access the WBDR, go to: <https://wbdr.realq.se/login/>

For WBDR support contact us at → wbdr@wfh.org