PATIENT SUMMARY CHART

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For more information, contact us at wbdr@wfh.org

WE HAVE A NEW FEATURE FOR YOU!

What is the Patient Summary Chart?

The Patient Summary Chart is a one-page summary of each patient's clinical events from the time they entered the WBDR.

What data are in the Chart?

All the data that has been entered in the WBDR including Baseline data, Baseline visit, Follow up Visit, Treatment data, and all the Functional scales (Quality of life results, EQ5D5L, HJHS, etc).

The more that is entered, the more data will be shown in just 1 page!

What are the benefits?

Besides seeing all data in 1 page and on a timeline in a chart, we have included Annual Bleeding Rate (ABR), Annual Joint Bleeding Rate (AJBR), and Annual Factor Use (AFU) calculations as the additional benefit of this new feature. This will enable the clinicians to review patient records prior to consultation, and to better plan for care and treatment of the patient.

Do I need to re-enter data in WBDR?

Not at all. The data have been summarized from all records entered in the WBDR. As long as your data are complete and accurate, the chart will be updated. This is a new WBDR tool that you will love.

Who can have access to the Chart?

Only those with log-in access to the WBDR database will have access.

Where is this chart in the WBDR?

The patient summary is easy to locate. Once the patient is selected, go to Patient Data, and Patient Summary Chart can be found there!!

Patient data ▾ Predefined queries ▾
Patient Summary
Patient summary chart
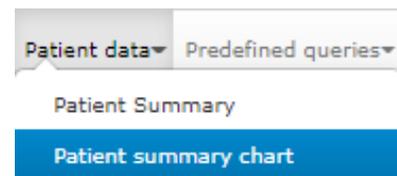
Sex*:	Current age (Years):	Date of birth*:	Clinic:
Male	10	01-Mar-2010	TEST Montreal HTC
Hemophilia type*:	**Date of diagnosis*:**	**Age at diagnosis (Months):**	**Date of registration in WBDR:**
A	10-Mar-2011	12	23-Apr-2020
Severity*:	**Factor Level (%)*:**	**Date of test*:**	**Weight (kg)***
Severe (<1%)	0.99	10-Mar-2011	30 (06-Jul-2020)

ABR	AJBR	Annual factor use	← HIGHLIGHTS
17 (2020)	11 (2020)	932 500 (2020)	ABR, AJBR and AFU are calculated!!
4 (2019)	4 (2019)	957 100 (2019)	
		672 500 (2018)	

WBDR
WFH World Bleeding Disorders Registry

WFH
WORLD FEDERATION OF HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA

Patient summary chart

Patient Summary Chart displays important and individualized patient information that has been summarized from all medical records entered in the WBDR.

Fields identified with an asterisk (*) are part of the Minimal Dataset of the WBDR. These fields are mandatory for all patients. Fields that do not have an asterisk (*) are part of the Extended Dataset. These fields are recommended but not mandatory.

1 — Select graph
2 — Date
2 — Update
3 — PDF Report   Open report
5 — Drugs | Series

Number of bleeds reported since last visit

Clinical trial - Gene Therapy
NovoEight
Adynovate

Inhibitor test
Hospitalization
EQ-5D-5L
HJHS
FISH
WFH Score (Gilbert)
Joint disease
Range of motion (Ankle)
Range of motion (Elbow)
Range of motion (Knee)

How can you use the chart?

1 = Select the graph to display. The options include: Number of bleeds reported, HJHS and WFH Gilbert score

2 = Select the time interval and click 'update' to display data

3 = Click on PDF Report, then click 'Open report' to download and print the Chart

4 = Click on 'Printer' image to download and print the Chart. **The data will be shown in just 1 page!** 👍

5 = Select between drugs type or series of data that are shown in the graph, including number of bleeds, HJHS joint score, WFH Gilbert score (depending on the graph selected from #1)

6 = Red dots represent bleed events (i.e. from the Chart above, in April 2019, this patient reported bleeds)

Hint…..Move the mouse over the dot or click on the dot to see more details of that bleed

7 = Color bars represent treatment (i.e. from the Chart above, in April 2020, this patient reported treatment)

Hint …..Move the mouse over the bar or click on the bar to see more details of that treatment

8 = Event bars including Inhibitor test, hospitalization, EQ5D5L, and Functional scales
(i.e. from the Chart above, in May 2019, this patient had inhibitor test with positive result (red +) and in November 2019, another inhibitor test was done with negative result (green -).

Hint …..Move the mouse over the symbol at the event bars or click on the symbols to see more details.