



WORLD BLEEDING DISORDERS REGISTRY

# Using Data to Improve Care for People with Bleeding Disorders



# MAIN MESSAGES

- 1 Patient data, the foundation of clinical decisions and health policies, can play a transformative role in the lives of people with bleeding disorders (PWBD). However, gaps in the availability, quality, and usability of these data are common, particularly in lower-income countries — the countries that stand to benefit most from using their data to improve the lives of PWBD.
- 2 Lack of a framework, technical capacity and resources, along with low prioritization, work together to hinder the collection and registration of data relevant for improving patient care, informing clinical decisions, and advocating for better care.
- 3 These challenges can be addressed through the provision of a data collection tool, such as the World Bleeding Disorders Registry, and accompanying support and training to enhance capacity to collect, maintain and use high quality data.
- 4 Ensuring a commitment to support the production of global data and evidence remains a central priority of the WFH towards our mission of **Treatment for All**.

# PATHWAYS TO IMPROVING PATIENT CARE WITH DATA

## PATHWAY 1: Providing a framework for HTC's to collect, store and use data

Database infrastructure is a prerequisite for collecting, storing, processing, and using data; however, the majority of treatment centers around the world, particularly in lower-income countries, lack the technical capacity and infrastructure to do so. The WBDR provides a simple and free platform to Hemophilia Treatment Centers (HTCs), with a full WFH support team to guide HTC staff in the implementation and use of the WBDR.

The WBDR is a powerful tool allowing clinicians to observe the clinical course of their patients, to understand variations in treatment and outcomes, to monitor safety and to measure the quality of care provided.

## PATHWAY 2: Improving Clinical Care

The first step to improving the quality of care is to analyze existing data to understand both the patient population and a center's organization of care to identify areas for improvement.

This data can then be used to establish a baseline for patient outcomes and improvements in the organization of care. Data collected at each follow up visit can be compared to the baseline visit to assess changes in patient outcomes over time.

Hemophilia treatment centers participating in other WFH programs, such as WFH Humanitarian Aid, Path to Access to Care and Treatment and the Twinning program, can use the WBDR to track patient progress and outcomes while participating in these programs. It is a simple and useful way to obtain evidence-based outcomes and demonstrate improvements in the clinical care provided to patients through WFH programs.



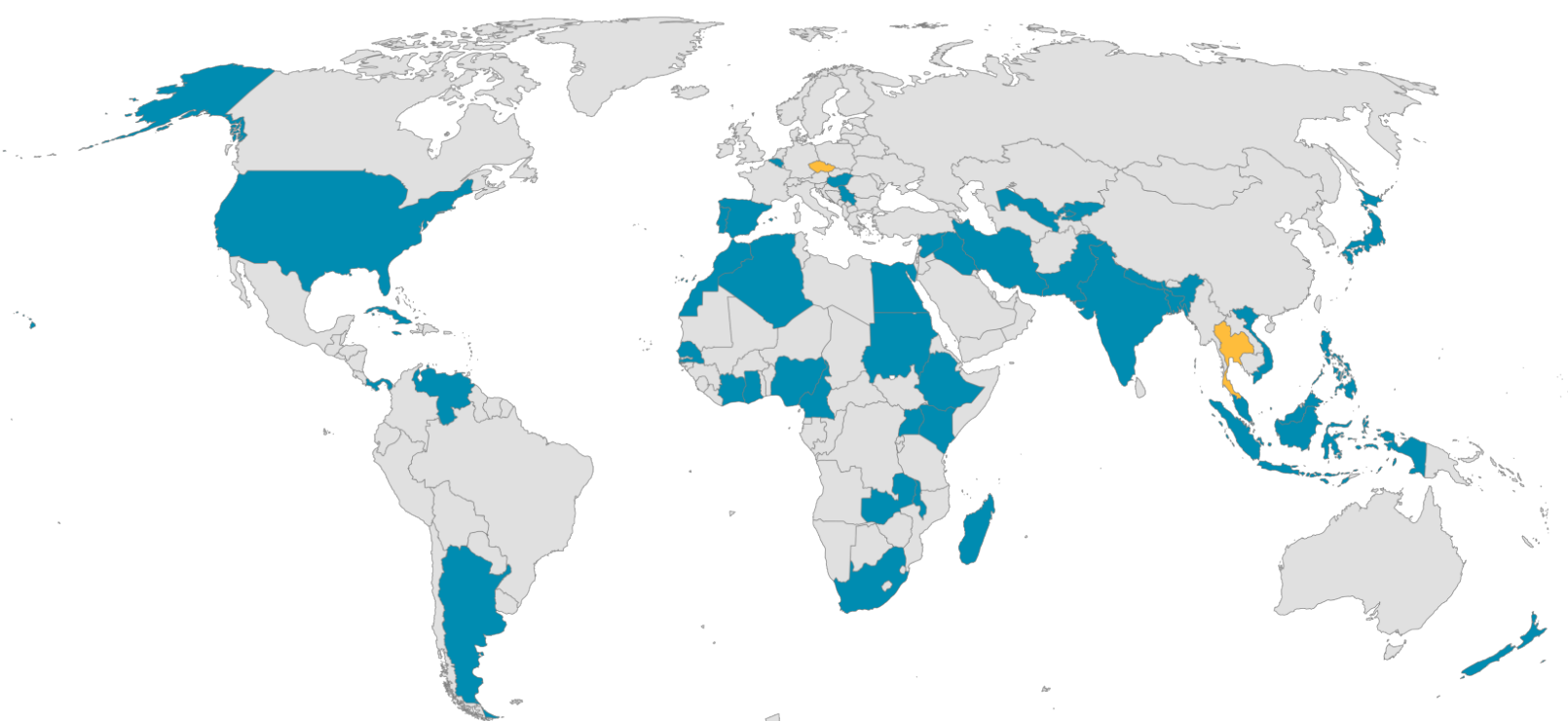
“The WBDR has enabled us to store our patient data in a systematic and timely manner. Using the patient specific Clinical Summary chart in the WBDR, I can quickly view the entire clinical history of my patients. This is a great tool to use as a guide for my clinical decisions and as a discussion aid with my patients.”

**DR. TITILOPE ADEYEMO, LAGOS UNIVERSITY  
TEACHING HOSPITAL HTC, NIGERIA**

**96** HTC's from **46** countries  
now have access to the WBDR to monitor  
the clinical course of their patients\*

\*as of February 2022

## PARTICIPATING COUNTRIES IN THE WBDR



### ■ Enrolled (46)

Algeria	Hungary	Malaysia	South Africa
Argentina	India	Morocco	Spain
Bangladesh	Indonesia	Nepal	Sudan
Barbados	Iran	New Zealand	Syria
Belgium	Iraq	Nigeria	Uganda
Cameroon	Jamaica	Pakistan	United States
Ivory Coast	Japan	Panama	Uzbekistan
Cuba	Kenya	Philippines	Venezuela
Egypt	Kyrgyzstan	Portugal	Vietnam
Ethiopia	Madagascar	Senegal	Zambia
Ghana	Malawi	Serbia	

### ■ Data Linkage (2)

Czech Republic  
Thailand

## PATHWAY 3: Data-informed Advocacy

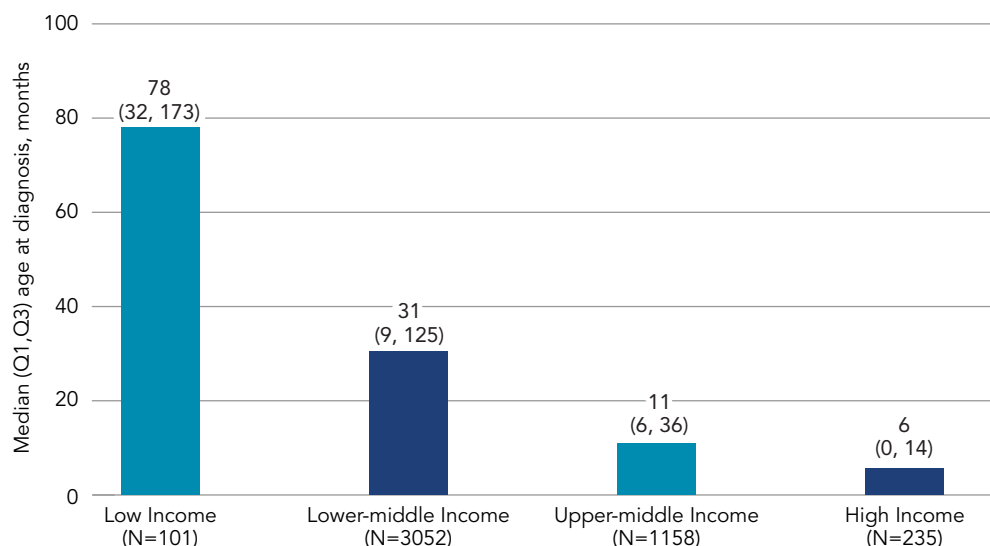
Standardized and harmonious data, collected in one global database, allows the identification of disparities in care globally. Highlighting these disparities is an essential step towards reducing the gaps in care between countries.

Simply providing HTC and national member organizations (NMOs) with better access to their own clinical data, aggregated and summarized for easy understanding, enables health care providers, patient advocates, and patients and families to use these data to advocate to improve the lives of PWB.

The WBDR allows clinicians to monitor the quality of care provided to their patients, while offering comparable estimates from other HTCs and countries on which they can benchmark their own progress. Data on patient outcomes provide advocates the essential evidence on which to base their advocacy initiatives and make informed decisions.

The median age of diagnosis is an indicator of the level of care available in a country. PWB living in low income countries are diagnosed much later in life compared to their peers living in high income countries: at 78 months vs 6 months. A later diagnosis means later access to treatment and more health consequences as a result of bleeding events.

Median Age at Diagnosis of Severe PWB by GNI\*, months



\*Gross National Income categories are based on the World Bank Group 2021 rankings

Source: World Bleeding Disorders Registry, March 2022

## PATHWAY 4: Facilitating Research

A registry of patient data helps facilitate research on important topics, ranging from the natural history of disease, to the efficacy of treatment regimes. The WBDR Research Support Program (RSP) offers small research grants to participating HTC's, encouraging them to use their data for research.

Coupled with the necessary training and education on the fundamentals of research design and implementation, the WBDR RSP offers HTC's a chance to learn the value of registries in enhancing patient care and to apply their skills in research.

Grant winners are encouraged to submit the results of their research to international conferences and to scientific journals. Data analysis and writing support are offered by the WBDR Research Team.

### WBDR Research Support Program Results (2018–2021)



23

Projects funded



14

Countries



27

Accepted Abstracts at  
International Conferences



“In Nepal, like many lower income countries, there is a dire need for sustained government support for hemophilia care. With a lack of reliable, high-quality data on the level of care available and on patient outcomes, it has been difficult to demonstrate the need for more support to decision makers. Nepal began using the WBDR to collect standardized data in 2018, providing them much needed data and evidence on which to support their advocacy initiatives. With these data, doctors in Nepal can now provide evidence to decision makers demonstrating a sub-optimal level of care and treatment available to PWH in Nepal, which has led to higher rates of bleeding and disability among PWH, compared to PWH in countries with better government support.”

**DR. BISHESH POUDYAL, CIVIL SERVICE HOSPITAL,  
KATHMANDU, NEPAL**

## PATHWAY 5: Informing and establishing adherence to treatment guidelines

Treatment guidelines serve as a useful tool for health care professionals and PWBD; they are meant to guide clinical decisions, reduce practice variation and measure quality of care. Ultimately, the goal of guidelines is to improve patient outcomes through a change in evidence-based clinical practices.

WBDR data can be used to measure the adoption of the WFH Guidelines for the Management of Hemophilia and the quality of care HTC's provide. These data can serve as a useful benchmark for HTC's to monitor improvements in their own clinical practice over time and can be used as a basis for comparison with other countries.

Having both the clinical practice recommendations and the data to monitor improvements in patient care and outcomes, can help HTC's achieve higher healthcare standards for their patients.



“The WBDR data provides the essential link between clinical practice & adherence to Treatment Guidelines, resulting in improved patient outcomes — and that is what we are all trying to achieve!”

**DR. TAHIRA ZAFAR, RAWALPINDI HTC,  
RAWALPINDI, PAKISTAN**

## PATHWAY 6: Clinical trial candidates

Developing countries are grossly under-represented in global clinical trials, despite comprising nearly 90% of the worldwide burden of disease, contributing to sustained health inequity. One of the many challenges to conducting clinical trials

in lower-income countries is the identification of eligible patients. Having a registry of patients through which clinicians can identify potential candidates, will help break down some of the barriers to participating in clinical trials.



## PATHWAY 7: Patient-reported outcome data

Patient-reported outcome data are playing an increasingly important role in health care decisions at all levels. The value in providing PWH with a mechanism to track and monitor their own health outcomes, as well as in supporting regulatory and clinical decisions is increasingly being recognized.



myWBDR, a mobile application associated with WBDR, was developed to capture patient-reported data for PWH participating in the WBDR.

The benefits of myWBDR include:

- Quick and easy entry of bleed and treatment data
- Track changes in health status through EQ-5D-5L and PROBE
- Provides a feedback mechanism directly to PWH to track their own progress in a visually meaningful way
- myWBDR data are stored in the WBDR database, allowing health care providers to track their patient data, including adherence to treatment and severe bleeds
- Functions offline, allowing data to be recorded without an internet connection
- Eliminates the need for paper diaries



From left to right: Dr. Jaco Joubert (Head of Department), Professor Marius Coetzee (Affiliated Associate Professor), Dr. Leriska Haupt (Senior Haematologist), Department of Haematology and Cell Biology, School of Pathology, University of the Free State, Bloemfontein, South Africa

“Increasingly PWH from Bloemfontein HTC are using myWBDR mobile application to keep clinically useful records of their bleeds, treatment, prophylaxis, and quality of life. From the PWH’s perspective, myWBDR app enables them to take control of their health. It provides PWH a better understanding of the relationship between their treatment and their health outcomes, and they can use this information to improve their care. For clinicians, myWBDR app provides real-time Patient-Reported Outcome data, which we can use to plan for better care and treatment. The myWBDR is a tool for promoting responsibility and doctor-patient teamwork.”

**PROFESSOR MARIUS COETZEE, UNIVERSITY OF THE FREE STATE, BLOEMFONTEIN, SOUTH AFRICA**

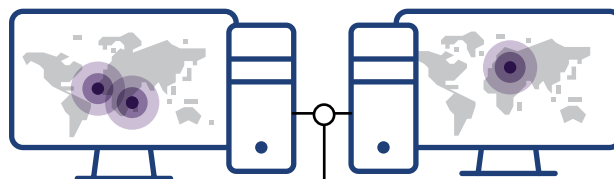
## PATHWAY 8: Re-purposing existing national registry data for greater value

Significant and numerous gaps in evidence supporting care of people with hemophilia still exist. Given the rarity of hemophilia, pooling data from patients around the world will enable researchers to use advanced statistical methodology on a larger sample size that would otherwise not be possible.

A variety of regional and national registries for hemophilia exist around the world. In an effort to pool these resources and maximize the utility of data, an international data harmonization and integration project was developed which aims to link existing patient registries with the WBDR. Linking registries at the patient level allows the quantity of data on PWH from around the world to be maximized and to make the best use of data in a limited data environment.

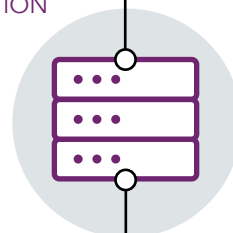
### NATIONAL HEMOPHILIA REGISTRIES

MULTIPLE LOCATIONS

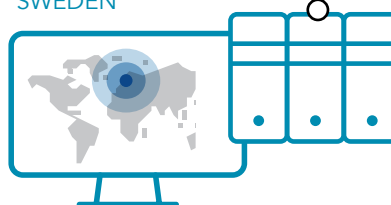


### DATA MAPPING

- TRANSFORMATION
- INTEGRATION



WBDR  
SWEDEN



# COUNTRY SPOTLIGHT

## Using data to improve patient care in Thailand and Czech Republic



“As a result of collaboration between the Thai Society of Hematology (TSH) and the WBDR, the minimal data set on patients with hemophilia from Thailand from our existing registry; the Hereditary Bleeding Disorder Registry has been transferred to the WBDR through the use of a simple and efficient ‘Magic Button’. As a result, data on 300 patients from Thailand are now part of the WBDR.”

**DR. AMPAIWAN CHUANSUMRIT, INTERNATIONAL HEMOPHILIA TRAINING CENTER (IHTC), BANGKOK, THAILAND**



“Disease-specific registers are a way to maximize the use of a limited amount of available data on rare diseases in a long-term and attainable way. Pooling and sharing data on an international level is the optimal way to increase real-world evidence in this field. This gives us the chance to further improve care worldwide. This is the reason why the Czech National Haemophilia Programme Registry appreciates our cooperation with the WBDR.”

**DR. JAN BLATNY, CZECH NATIONAL HAEMOPHILIA PROGRAMME REGISTRY (CNHPR), PRAGUE, CZECH REPUBLIC**

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



**WBDR**  
WFH WORLD BLEEDING  
DISORDERS REGISTRY



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