

WORLD BLEEDING DISORDERS REGISTRY

Advancing care through
data collection and research

2024 Impact Report



WBDR
WFH WORLD BLEEDING
DISORDERS REGISTRY

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ABOUT THE WFH

The World Federation of Hemophilia (WFH) is a non-profit organization dedicated to improving and sustaining care for people with inherited bleeding disorders around the world.

At the WFH, national member organizations (NMOs) and healthcare professionals (HCPs) work together to provide care for people with inherited bleeding disorders around the world. We partner with governments and hemophilia treatment centres to enhance knowledge through training and provide tools they need to identify, support and treat people living with bleeding disorders in their communities, while promoting global advocacy and collaboration to achieve our common goals. To find out more about the WFH, visit www.wfh.org.

ACKNOWLEDGEMENTS

The WFH Data & Research department who contributed to the creation of this report: Donna Coffin, MSc; Emily Ayoub, PhD; Ellia Tootoonchian, MPH; Pamela Dakik, PhD and Toong Youttananakorn, PhD

Special thanks to Ticiana Carvalho Pereira for her contribution to the statistical analysis of the WBDR data.

MISSION OF THE WORLD FEDERATION OF HEMOPHILIA

Improve and sustain care for people
with inherited bleeding disorders
around the world.

MESSAGE FROM THE WFH PRESIDENT AND VICE PRESIDENT, MEDICAL

April 2025

Dear members of the bleeding disorders community: we are pleased to present the 2024 World Bleeding Disorders Registry (WBDR) Impact Report.

Our goal is to ensure that the data collected through this platform:

- 1. Supports research and advocacy efforts**
- 2. Informs clinical decision-making**
- 3. Enhances care for individuals with bleeding disorders**

Now in its seventh year, the WBDR continues to be an important initiative that allows for the systematic collection of real-world clinical data on people with hemophilia (PWH) and people with von Willebrand disease (PwVWD) worldwide.

As of December 31, 2024, more than 17,000 PWH and PwVWD from 124 hemophilia treatment centres (HTCs) across 47 countries have joined our efforts in collecting these invaluable data. This collective effort has strengthened the understanding of patterns, disparities and gaps in treatment and care management faced by PWH, PwVWD and healthcare providers.

This report provides a comprehensive overview of the growth, achievements and program development in the past year along with the positive impact the WBDR has had on research and advocacy. With this progress, we hope that the WBDR continues to serve as a global benchmark for understanding clinical practices, improve health outcomes and address equity in care.

On behalf of the WFH, we extend our sincere gratitude to the dedicated healthcare providers, PWH, and PwVWD who contribute to this critical initiative. We look forward to further collaborations with HTCs interested in joining the WBDR as we continue advancing our mission of Treatment for All.

We would also like to recognize our visionary partners who have made it possible for us to develop this registry: Sobi; as well as our collaborating partners: F. Hoffmann-La Roche, Grifols, Novo Nordisk, Pfizer & Sanofi.

Sincerely,



Cesar Garrido
President



Glenn Pierce, MD, PhD
Vice President, Medical



ABOUT THE WBDR

Launched in January 2018, the WBDR provides a platform for HTC's around the world to collect standardized data on PWH and PwVWD. The WBDR is a prospective, longitudinal, observational registry. It is a privacy-protected online web-based data entry system, that allows for the collection of individual patient data, thus providing a clinical profile for each patient.

WBDR METHODOLOGY

Participating HTC's are at the forefront of recruiting patients and entering confidential and de-identified patient data into the WBDR database. The WFH works closely with all interested HTC's to guide and assist them through the required steps of participating in the program, including obtaining Institutional Review Board approval, recruiting patients, and managing their data.

The WBDR is open to all people with hemophilia A or B and PwVWD who are a patient at a participating HTC. The HTC's are asked to invite all consecutive people with hemophilia A and B, and VWD at their clinic to enrol in the WBDR to minimize the risk of selection bias. All patients who agree to participate must provide informed consent.

DATA ACCESS AND GOVERNANCE

Each HTC has access only to the data they enter into the WBDR, and they cannot view data that are entered from any other HTC. Access to data for research and advocacy purposes will be available through the WBDR Research Governance Committee.

DATA PRIVACY

The WBDR database was developed through the collaborative efforts of the WFH, the Karolinska Institute, and BCB Medical – the latter two organizations based in Sweden. All patient information entered in the WBDR is de-identified and confidential. Data policy guidelines of BCB Medical adhere to the CE-mark (Conformité Européenne) and the U.K. standard IG SoC (Information Governance Statement of Compliance) and are compliant with the General Data Protection Regulation.

.....

The WBDR is open to
all people with
hemophilia A or B, and
VWD who are patients
at a participating HTC.

.....

WBDR KEY OBJECTIVES

Report
patient data

Facilitate
research

Inform advocacy
initiatives

Provide framework for
HTCs to collect, store
and use data

Inform and establish adherence
to treatment guidelines

Repurpose existing
data for greater value

Identify clinical trial
candidates



DATA
COLLECTION



RESEARCH
AND INSIGHTS



EVIDENCE-BASED
ADVOCACY



POLICY AND CARE
IMPROVEMENTS

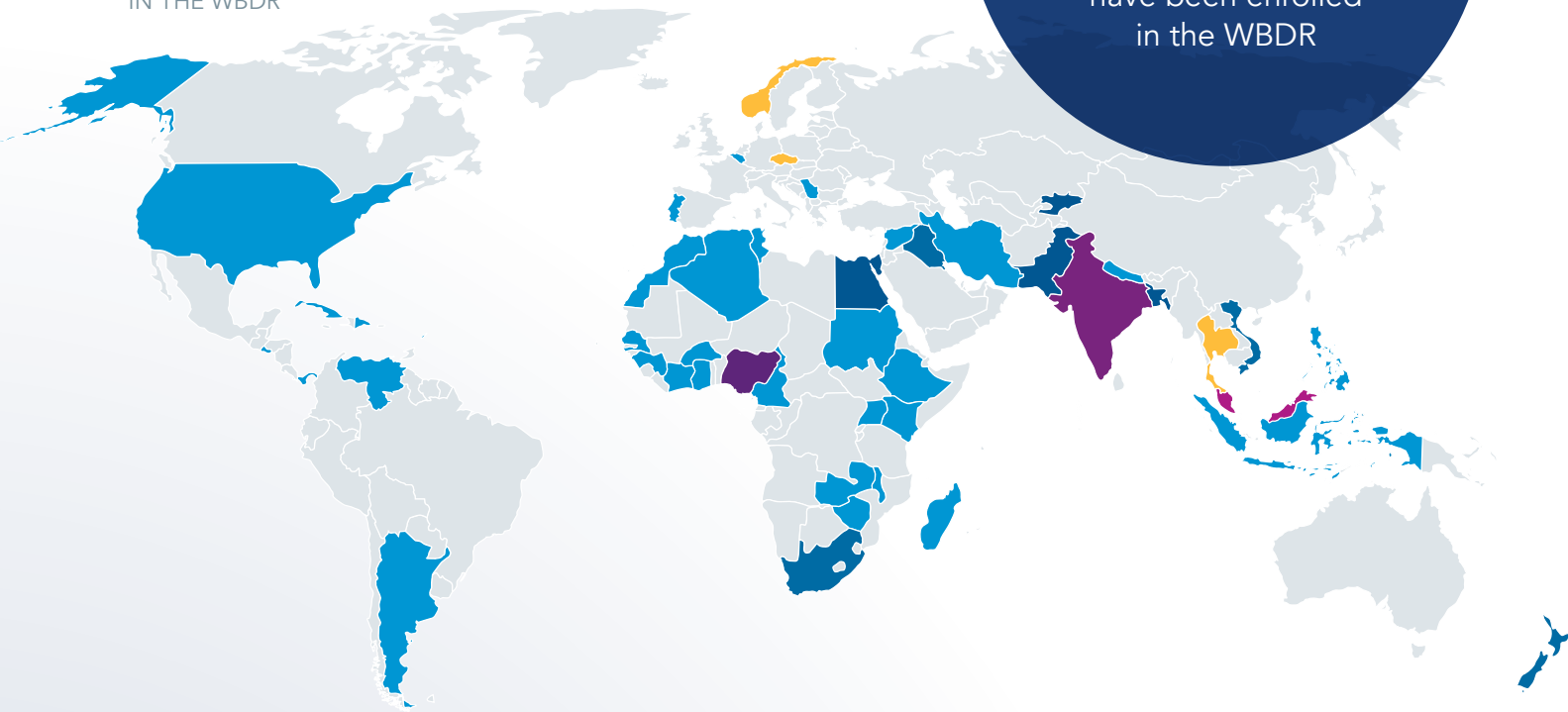


GLOBAL REPRESENTATION IN THE WBDR

Figure 1

COUNTRIES AND HTC'S PARTICIPATING IN THE WBDR

17,059
PWH AND PwVWD
have been enrolled
in the WBDR



1 Number of HTC's per country 17

Data Integration

Algeria	2	Ethiopia	1	Malawi	1	Serbia	1
Argentina.....	2	Ghana	1	Malaysia.....	17	South Africa	3
Bangladesh.....	6	Guinea.....	1	Morocco	2	Sudan	1
Barbados	1	India.....	8	Nepal.....	1	Syria.....	1
Belgium	1	Indonesia	1	New Zealand	3	Thailand.....	8
Burkina Faso	1	Iran.....	1	Norway	1	Tunisia.....	1
Cameroon.....	1	Iraq	3	Nigeria.....	7	Uganda	1
Cuba	1	Ivory Coast.....	1	Pakistan	4	USA.....	1
Czechia	16	Kenya.....	2	Panama.....	1	Venezuela	1
Dominican Republic ...	1	Kyrgyzstan	4	Philippines	1	Vietnam	3
Egypt	4	Lesotho.....	1	Portugal	1	Zambia.....	1
El Salvador.....	1	Madagascar	1	Senegal.....	1		

For a complete list of HTC's, please refer to Appendix 1

WBDR SINCE 2018

HEMOPHILIA

47

COUNTRIES
REPRESENTED

124

HTCs
PARTICIPATING

15,395

PATIENTS ENROLLED



15% INCREASE
since 2023

VON WILLEBRAND DISEASE

(since 2023)

24

COUNTRIES
REPRESENTED

53

HTCs
PARTICIPATING

1,664

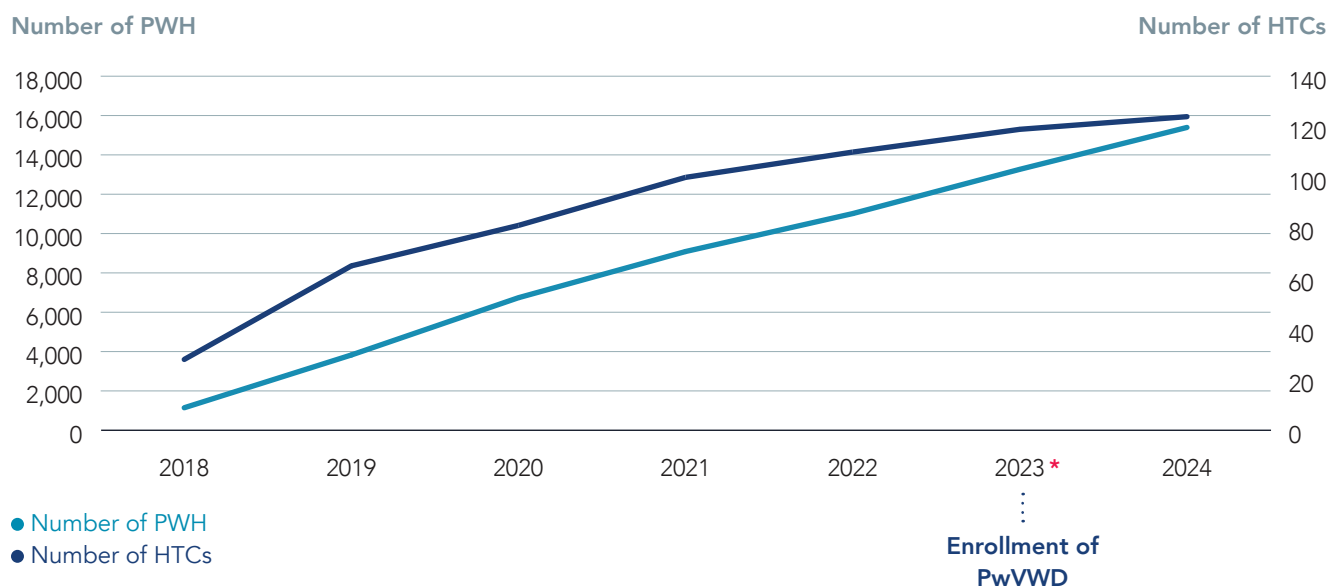
PATIENTS ENROLLED



67% INCREASE
in enrolled PwVWD
since 2023

Figure 2

PWH AND HTC ENROLMENT IN THE WBDR, JANUARY 2018 – DECEMBER 2024



EXPANDING DATA COLLECTION

LAUNCH OF WBDR DATA VISUALIZATION DASHBOARD

To maximize the use of WBDR data, the Data Dashboard was launched in 2024. The Data Dashboard is a powerful tool designed to show real-time insights, which enhance understanding of care and treatment for PWH and PwVWD globally.

This interactive tool summarizes and transforms the WBDR data into visualizations, providing users access to key data and trends.

The aim of the Data Dashboard is to provide a comprehensive, visual overview of important metrics and enables users to identify patterns, correlations, and disparities in hemophilia and VWD care around the world.

The Data Dashboard allows HCPs, researchers and advocates to analyze trends and gaps in diagnosis, treatment and care, with a goal to improve patient outcomes, resource allocation and health policies.

By making the WBDR data more accessible, we hope to highlight the importance of this data collection initiative and its critical role in positively impacting the bleeding disorders community and improving care for PWH and PwVWD.



Click here to explore
[the Data Dashboard](#)
or scan the QR code



myWBDR MOBILE APPLICATION

A powerful tool for WBDR participants

The myWBDR mobile application empowers patients to play an active role in their treatment and care. Participants use the application to record bleeding information, level of pain, treatments and health status using EQ-5D-5L and PROBE.

myWBDR was officially launched in May 2022. Since then, it has been adopted in 18 countries and has accumulated over 1,000 bleed records and more than 8,000 treatment records, signifying its impactful role in gathering patient-reported data, improving clinical management, and generating valuable evidence for bleeding disorders research and decision-making. myWBDR also serves as an important tool for HCPs to monitor the health status of their patients and enhance the quality of care and treatment provided. It is accessible through HTC's participating in the WBDR. Those interested can reach out to their HCP to initiate the sign-up process.

Further inquiries or requests for additional information about myWBDR can be directed to myWBDR@wfh.org.

Available in:

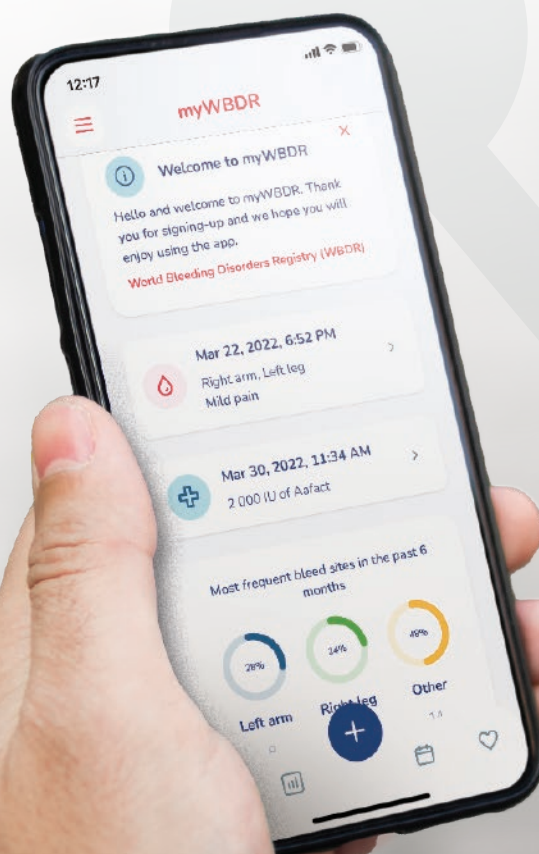
Arabic, English, French, Hindi, Portuguese, Russian, Spanish, Thai, Urdu, and Vietnamese.



App Store



Google Play



COLLECTING DATA ON WOMEN AND GIRLS WITH BLEEDING DISORDERS

In 2023, in line with the WFH strategic priorities, changes to the WBDR database were implemented to collect female-specific data on women and girls with bleeding disorders (WGBD).

The changes included the addition of a Pregnancy Module where the impact of bleeding disorders on the course of the pregnancy, the pregnancy outcome, and the post-partum phase is reported. Additionally, female-specific bleeds and comorbidities were added.

In parallel, a training dedicated to the importance of data collection on WGBD was provided to all WBDR HTC. WBDR trainings emphasize the importance of data collection for WGBD and its impact on research and advocacy. To assess the impact of outreach and training, enrolment of women and girls with VWD and hemophilia is regularly monitored.

In 2024, a continuous increase in the rate of enrolment of women and girls was observed (Figure 3). Unsurprisingly, 55% of all PwVWD in the WBDR are female. Evidence from the WBDR data is essential for advocacy and awareness campaigns and represent an important step towards improved diagnosis and care of WGBD globally.

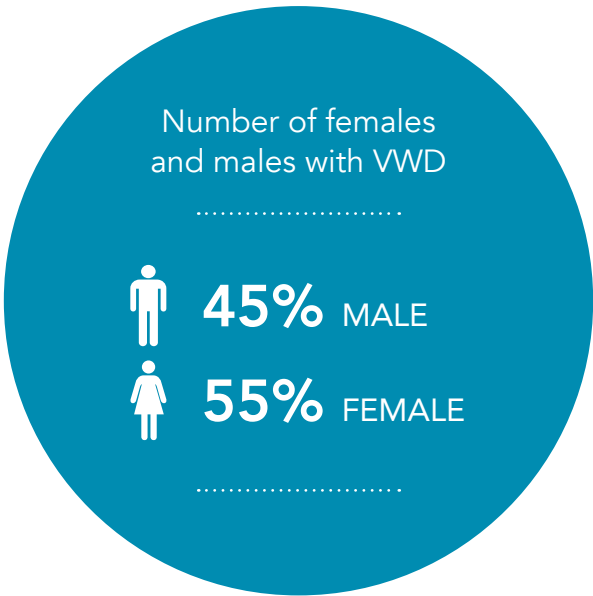
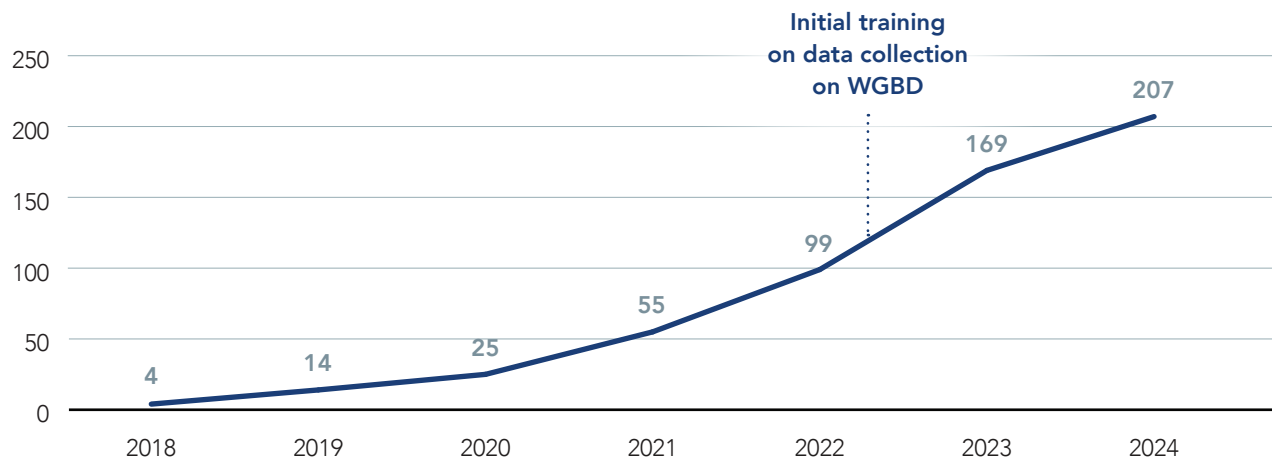


Figure 3

NUMBER OF FEMALES DIAGNOSED WITH HEMOPHILIA (INCLUDING ALL HEMOPHILIA TYPES AND SEVERITIES) ENROLLED IN THE WBDR OVER TIME



WBDR PROGRAMS AND TRAINING

The WBDR aims to support HTCs on using WBDR data for research and advocacy to advance care clinically and at the country level.



WBDR TRAINING AND CAPACITY BUILDING

Annual data entry training

The WBDR Annual Data Entry Training is offered to all staff from participating HTCs around the world.

The main objectives of the training are to provide:

- An update on the WBDR programs and changes to the WBDR database
- A refresher on WBDR data entry practices
- A platform for participants to ask questions
- Recommendations on how to improve data quality by sharing common data quality issues

In 2024, 135 attendees from over 100 HTCs joined the training. Questions from participants covered several topics including: correcting errors, Quality of Life (QoL) questionnaire and Functional Assessments, clarifications on the treatment and bleeding modules, and exporting WBDR data to use for research purposes.

In the follow-up survey, participants suggested adding data fields such as more detailed family history as well as the patient's regional origin.

This yearly training remains important for the improvement of the WBDR program as it connects the HTC with the WBDR and allows us to receive constructive feedback from registry users.



.....
40 PARTICIPANTS
from
26 COUNTRIES
.....

WBDR Investigator Meeting: WFH 2024 World Congress in Madrid

The WFH 2024 World Congress in Madrid saw multiple WBDR investigators from around the world come together. The WBDR team took this opportunity to further strengthen the WBDR global network.

The meeting had three main objectives:

- Share recent WBDR news with the investigators
- Provide a platform for investigators to share their feedback and challenges
- Encourage networking and exchange of ideas

During this meeting, the participants were asked for their feedback on the functionalities of the database, and the challenges in data collection.

Key insights included:

- 83% of the investigators plan to use the data for research
- 76% of respondents plan to use WBDR for patient management
- 66% of participants identified a shortage of staff as the primary barrier to effective data collection

In response to the feedback, the WBDR team added new research and collaboration initiatives to their 2025 strategic plan. As a direct outcome of the meeting, two collaborative research studies between WFH and HTCs were launched.



Africa data workshop

In 2024, the WBDR team organized a data workshop in Cape Town, South Africa which brought together healthcare providers and patient advocates from 17 countries in the region. The aim of the workshop was to provide participants the opportunity to learn about the effective use of WBDR data in research and advocacy, share insights and exchange ideas on ways to advance hemophilia and VWD care in Africa.

Participants gained insight about the importance of generating evidence for research and advocacy. Saliou Diop, MD from Senegal led an informative session, introducing research methodologies and informed participants of the steps to develop research proposals and publish scientific articles. Additionally, Emna Gouider, MD from Tunisia demonstrated how evidence-based approaches can influence policy changes for better patient outcomes.

During this workshop, participants worked together to develop a research proposal to address their regional needs, focusing on improving diagnosis and treatment for PWH and PwVWD. They also had the opportunity to develop an advocacy plan and outline actionable steps to effectively engage and influence decision-makers.

The workshop highlighted the importance of building national registries and leveraging data to inform policies, support research efforts, and advocate for better patient care.





Post-training, percent of participants with
EXCELLENT KNOWLEDGE OF WBDR
PROGRAMS

3% TO 62%

81%

of participants indicated that
THEY WERE LIKELY OR HIGHLY LIKELY
TO USE WBDR DATA FOR RESEARCH
AFTER TRAINING



Through this collaborative effort, a
consensus-driven list of prioritized advocacy
indicators for hemophilia care in Africa
was developed.

These indicators can provide a framework for focusing data
collection efforts on measures that are both relevant and
impactful, to support data-informed advocacy. This exercise
offered a valuable starting point for African countries
initiating or refining their data collection efforts to better
understand their patient needs and help establish
baseline measurements against which improvements can
be monitored.

An abstract titled “Developing a Prioritised Set of Advocacy
Indicators for Enhanced Haemophilia Care in Africa Using
WBDR and AGS Data”, documenting the process and
results was highlighted at the European Association for
Haemophilia and Allied Disorders (EAHAD) Congress in
February 2025.



✦ [Click here for the abstract
or scan the QR code](#)

WBDR HTC FUNDING PROGRAM

The WBDR HTC Funding Program (HFP) provides financial support to WBDR HTCs in low and lower-middle-income countries to increase data collection capacity.

Every year, the program aims to support HTCs in the following areas:

- Collect comprehensive and standardized data
- Increase patient enrolment
- Ensure accurate recording of follow-up visits
- Promote the use of functional scales and Quality of Life (QoL) questionnaires

To date, HTCs have used this program for essential activities that have improved clinical practices, including data entry and management resources, patient support and education, infrastructure and equipment, communication and internet.



“Since joining the WBDR HTC Funding Program in 2020, we at Christian Medical College, Ludhiana, have experienced an improvement in the way we manage and utilize data for our patients with hemophilia. The program’s emphasis on efficient data entry processes, coupled with its robust monitoring and evaluation framework, has significantly streamlined our data capture methods. This enhancement not only facilitates more effective data management but also empowers us to conduct precise analyses tailored to our centre’s specific needs. The ability to examine our data helps us in refining patient care and advancing our research endeavours.”

—Professor Joseph John from Christian Medical College, Ludhiana, India

It is with great pleasure that we express our gratitude to the WBDR team through their funding of the HTC. Indeed, it has been five years since Madagascar has benefited from this program. The computer equipment has been provided and maintained, the essential IT supplies to register patients are used, the expenses linked to the internet connection are correctly covered, the person responsible for registering and monitoring patients is comfortable in his role, his relationships with other health providers and in his communications with patients living with hemophilia in Madagascar as well as their families. For all these reasons, the WBDR HTC financing program has the full gratitude of Madagascar HTC, on behalf of all Malagasy PWH.”

—Professor Olivat Rakoto Alson from the Madagascar CHU Joseph Ravoahangy Andrianavalona

WBDR HTC Funding Program impact

Since 2020, the WBDR HTC Funding Program has significantly advanced the data collection at participating HTCs, with over 30 HTCs from 21 countries receiving funding.

The data from the 2024 HTC performance review highlights several key accomplishments for funded HTCs:

100%

of HTCs in the program reported an increase in the number of **ENROLLED PEOPLE WITH BLEEDING DISORDERS AT THEIR CENTRE**

>70%

of HTCs reported growth in the **NUMBER OF PATIENTS WITH QoL ASSESSMENTS**

18%

of HTCs recorded **OVER 100% GROWTH IN QoL REPORTING**

>80%

OF HTCs HAVE INCREASED THE PROPORTION OF PATIENTS WITH FOLLOW-UP VISIT DATA, a crucial element for the longitudinal and prospective aspects of the WBDR study

80%

of HTCs with healthcare providers trained on the HJHS assessment demonstrated an increase in the **NUMBER OF PATIENTS WITH AN HJHS SCORE IN THE WBDR**

The WBDR HTC Funding Program has significantly improved data collection. The reported increase in patient enrolment and in the collection of longitudinal data allows for better patient representation at local and national levels, and for healthcare providers to monitor patient health more effectively and provide timely interventions.

By providing financial support, the program has enabled HTCs to collect more comprehensive and accurate data, which is crucial for understanding the needs of people with bleeding disorders and improving treatment protocols.



Click here for WBDR
HTC Funding Program
or scan the QR code



WBDR RESEARCH SUPPORT PROGRAM

The WBDR Research Support Program (RSP) awarded grants to seven HTC's in 2024. The funded research projects cover a diverse array of important topics aimed at improving hemophilia care and outcomes worldwide.

Key highlights since 2018:



24 countries involved



51 research projects funded



40 HTC's participated



>220,000 USD awarded



27 publications at international conferences

(including abstracts and featured articles)

One notable project is the Applications of Artificial Intelligence in Hemophilia, conducting a proof-of-concept study that models and reviews WBDR registry data to uncover potential innovations in care. Another key project is the Screening of Girls with Hemophilia and Von Willebrand Disease, focusing on identifying and supporting a vulnerable, often overlooked patient group.

Additional projects aim to enhance patient education, such as efforts to increase knowledge regarding joint health for patients and families, which is critical to improving long-term outcomes. The quality of life of patients on prophylaxis will also be examined, contributing valuable data to the growing body of knowledge on treatment impact. Additionally, the program supports initiatives like building patient capacity to report bleeds and treatment data via the myWBDR platform, enabling more accurate tracking and management of hemophilia. These are just a glimpse of the many exciting and innovative projects being supported through the WBDR RSP.

Each year, we highlight success stories from our HTC's presented on the international stage. For example, during the 2024 WFH World Congress, abstracts from two HTC's—HTC Ulin General Hospital and HTC Rajshahi in Bangladesh—were shared. The HTC's shared their findings and highlighted their research in hemophilia care.



Overall, the WBDR Research Support Program not only enhances research capabilities but also strengthens the global hemophilia community, bringing attention to critical areas such as early diagnosis, patient education, and data sharing. We continue to welcome new, creative initiatives that aim to improve care, treatment, and knowledge in the field of hemophilia and VWD.



Click here for WBDR
Research Support Program
or scan the QR code

Research Study from...

Indonesia

The quality of life among hemophilia patients in South Kalimantan, Indonesia

This project aimed to investigate the quality of life among PWH in South Kalimantan, Indonesia, where healthcare resources are limited, and patients are spread over a large geographical area. It focused on using WBDR data to assess whether education and intervention, such as physiotherapy, could improve the quality of life of PWH in this region. Conducted at Ulin General Hospital's HTC, this research focused on 46 PWH living in areas with limited healthcare resources. Over the course of the study, participants saw remarkable improvements in key areas of their lives. For example, patients with no mobility issues increased from 63% to 76.2%, while patients with no problem in self-care abilities rose from 67% to 88.1%, and pain-free days increased from 34.8% to 59.5%. The results of this study are the proof of benefits from education and tailored care, showing that even in resource-limited settings, PWH can experience a better quality of life with proper intervention and support.



Bangladesh

Clinical characteristics and therapeutic management of confirmed hemophilia cases registered in the hemophilia treatment centre at Rajshahi in Bangladesh

This project represents a significant success in filling a critical gap in hemophilia care within a resource-limited setting. Conducted at the Rajshahi Medical College Hospital, this research successfully gathered and analyzed data from 173 registered hemophilia patients in the WBDR, providing invaluable insights into their clinical characteristics and therapeutic management. The study found that 98% of the patients were male, with 94% of cases being Hemophilia A. 70% of patients had moderate disease severity whereas 58% of patients reported experiencing 1-3 bleeding episodes in the last six months. A key success of the study was its demonstration of the feasibility of gathering and analyzing clinical data in context of a developing country, offering a clear picture of the therapeutic needs.

The results highlighted the need for increased access to prophylactic treatment, as 95% of patients received on-demand therapy, while only 5% had access to prophylaxis. This research provides critical evidence for global hemophilia management that can help improved treatment strategies and patient outcomes in Bangladesh, paving the way for better care and informed decisions in the future.



INTERNATIONAL DATA INTEGRATION PROGRAM

In an effort to combine resources from existing hemophilia registries and maximize the utility of current data, WBDR established the International Data Integration Program in 2019, with the aim of facilitating data transfer from existing patient registries to the WBDR.

In 2024, the WBDR collaborated with Norwegian National Registry, in a pilot effort to use aggregated data to represent people with bleeding disorders from countries with existing national registries in the WBDR global data.

This was completed as a part of a proof-of-concept pilot to integrate high-income country data when patient-level data cannot be shared due to national data protection and privacy laws. The success of this new data linkage strategy allows other countries with strict patient data privacy and protections laws to share aggregated data without breaching local laws. This initiative widens the WBDR reach and improves patient representation in the WBDR global data.

.....

**Norway have shared aggregate data
(demographic, diagnostic, and clinical
data) on**

464 PWH and
483 PwVWD

.....

"We are happy that Norway PWH Registry is the first national registry to pilot the sharing of aggregated data with the WBDR. Our patients are now represented in the global WBDR data in this Report. We thank the WFH for their support in sharing the data."

—Pål Andre Holme, MD, Hematologist,
Oslo University Hospital, Norway

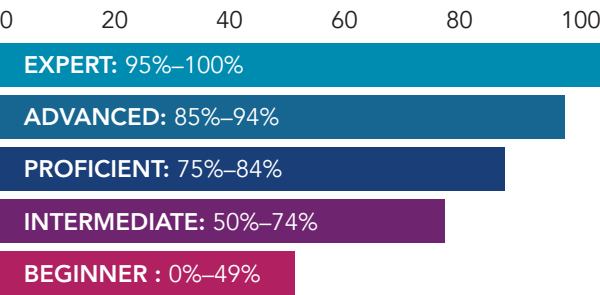
DATA QUALITY ACCREDITATION PROGRAM

Since its launch in 2018, the WBDR has offered a comprehensive Data Quality Accreditation Program (DQA) that includes a robust data cleaning and validation process.

This program is designed to improve data completeness, accuracy, and consistency. Through this program, HTC's receive data-entry training, data quality assessment, and ongoing technical support. The primary goal of the Program is to emphasize the importance of high-quality data within the registry and to equip HTC's with the essential tools and knowledge needed to achieve and maintain such standards.

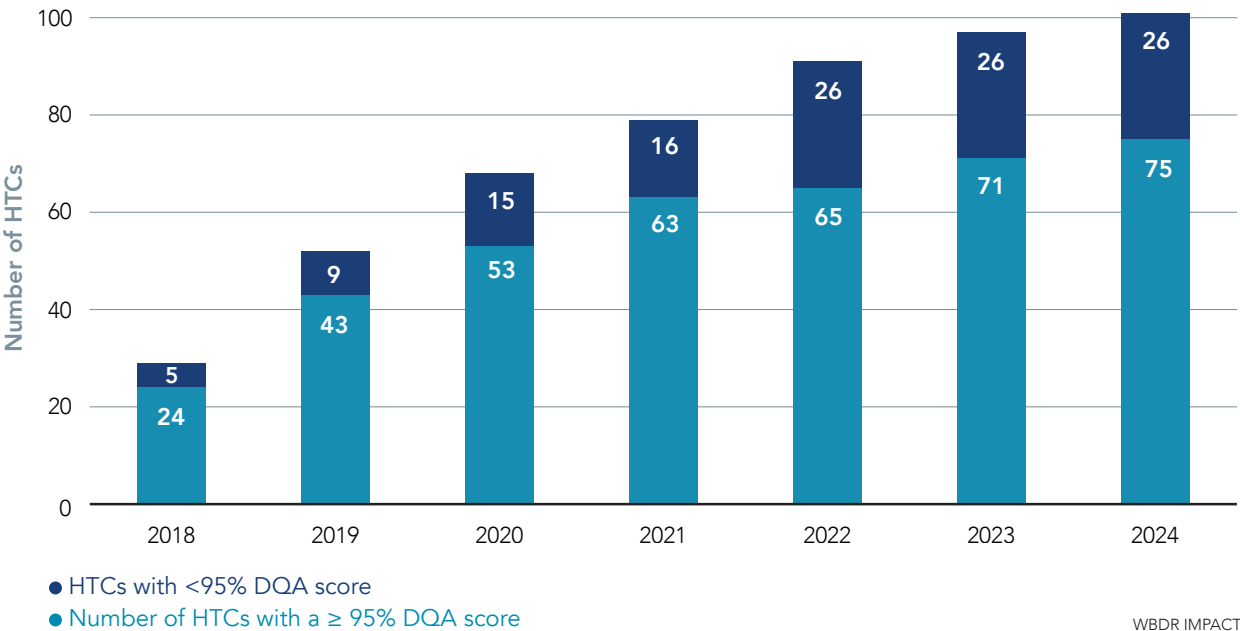
Each year, the WBDR team reviews data quality using the WBDR Data Quality Rating. HTC's are ranked based on their data quality scores, ranging from "Beginner" for scores between 0% and 49% to "Expert" for scores of 95% or higher (Figure 4). This enables individual HTC's to identify areas for improvement, ensuring that the registry remains a robust and credible source of real-world data.

FIGURE 4
DATA QUALITY SCORING SYSTEM



77% of HTC's
over the past seven years (2018-2024)
**HAVE CONSISTENTLY
ACHIEVED AN EXPERT-LEVEL
DATA QUALITY SCORE OF
95% OR HIGHER**

FIGURE 5
NUMBER OF HTC's MEETING DQA BENCHMARK (≥ 95%) OVER TIME



LOOKING AHEAD TO 2025

The WBDR data will continue to be an important source of evidence that offers insights into trends, treatment effectiveness, and care disparities, which ultimately inform policies, improve patient outcomes, and drive equitable access to treatment and care worldwide.

In 2025, the WBDR will continue to expand participation and foster stronger collaborations to ensure global representation. Additionally, capacity-building initiatives, such as training programs and data utilization workshops will be used to educate on the effective use of data for advocacy and decision-making.

Research projects will play a key role in identifying gaps in care and driving innovation in treatment and approaches. Currently, there are multiple research projects that are underway.

The first Indian collaborative study on hemophilia from the WFH WBDR

WBDR investigators have long initiated research studies using WBDR data. A pan-Indian, investigator-led research initiative is underway, with six WBDR HTC's participating. The study aims to describe demographics, diagnosis, and clinical care and outcomes for PWH enrolled at those centres. A comparative analysis on the regional and global care standards will be conducted. Identifying gaps in care is the first step towards improving hemophilia management in India. Investigators aim to submit a manuscript in 2025.

Evaluating the impact of WFH programs in Pakistan using WBDR real-world data

In collaboration with all four Pakistani HTC's and the Hemophilia Foundation of Pakistan (HFP), the WFH is conducting a study to assess the impact of WFH programs throughout Pakistan. The study aims to address the following research question: Has the introduction of WFH Programs (Humanitarian Aid, Training, PACT, WBDR, IHTC Fellowships) resulted in better patient outcomes?

The Retrospective - Prospective cohort study seeks to evaluate the outcomes of patients with severe hemophilia using WBDR data prior and post the implementation of the Programs (Intervention). Outcomes include hospitalization, Annualized Bleeding Rate, incidence of life-threatening bleeds, and impact on employment.

Assessing patient outcomes in El Salvador

In collaboration with El Salvador, a single centre observational study is being conducted to assess the sociodemographic, clinical characteristics, treatment patterns and health outcomes of the pediatric population with hemophilia A in the country.

.....
The WBDR through its
programs aims to

increase the capacity
for data-driven
research and advocacy
in 2025.
.....

WFH WBDR STEERING COMMITTEE

The WFH would like to thank the WBDR Steering Committee for their dedication to the development and implementation of the WBDR:

- Alfonso Iorio, MD, PhD, Co-Chair
- Emna Gouider, MD, Co-Chair
- Barbara Konkle, MD
- Saliou Diop, MD
- Cedric Hermans, MD, PhD
- Catherine Lambert, MD
- Glenn Pierce, MD, PhD, VP Medical WFH
- Cesar Garrido, President WFH



APPENDIX 1- PARTICIPATING HTC's

Country	City-Clinic
Algeria	<ul style="list-style-type: none"> • Annaba - Service d'hématologie CHU Annaba • Constantine - Unité hémophilie et maladies hémorragiques héréditaires
Argentina	<ul style="list-style-type: none"> • Bahía Blanca - CARDHE • Buenos Aires - Fundación de la Hemofilia and Instituto De Investigaciones Hematológicas "Dr. Mariano R. Castex"
Bangladesh	<ul style="list-style-type: none"> • Chittagong - Chittagong Medical College Hospital • Dhaka - Bangabandhu Sheikh Mujib Medical University • Dhaka - Dhaka Medical College • Dhaka - Dhaka Shishu Hospital • Dhaka - Lab One Foundation • Rajshahi - Rajshahi Medical College & Hospital
Barbados	<ul style="list-style-type: none"> • Bridgetown - Queen Elizabeth Hospital
Belgium	<ul style="list-style-type: none"> • Woluwe-Saint-Lambert - Cliniques Universitaires Saint-Luc
Burkina Faso	<ul style="list-style-type: none"> • Ouagadougou - CHU Pédiatrique Charles de Gaulles
Cameroon	<ul style="list-style-type: none"> • Yaoundé - CHU Yaoundé
Côte d'Ivoire	<ul style="list-style-type: none"> • Abidjan - CHU de Yopougon
Cuba	<ul style="list-style-type: none"> • Havana - Instituto de Hematología e Inmunología
Czechia	<ul style="list-style-type: none"> • Brno - University Hospital: Dpt. of Clinical Hematology • Brno - University Hospital: Dpt. of Pediatric Hematology • České Budějovice - Dpt. of Clinical Hematology • České Budějovice - Pediatric Dpt. • Hradec Králové - University Hospital: Dpt. of Pediatric Medicine • Liberec - Regional Hospital: Dpt. of Clinical Hematology • Olomouc - University Hospital: Dpt. of Pediatric Medicine • Olomouc - University Hospital: Haemato-Oncology Dpt. • Ostrava - University Hospital: Blood centre • Ostrava - University Hospital: Dpt. of Pediatric Medicine • Pilsen - Hemacentrum • Pilsen - University hospital: Dpt. of Biochemistry and Hematology • Pilsen - University hospital: Pediatric Dpt. • Prague - University Hospital in Motol: Dpt. of Pediatric Hematology and Oncology • Ústí nad Labem - Masaryk Hospital: Dpt. of Clinical Hematology • Ústí nad Labem - Masaryk Hospital: Pediatric Dpt. - Hematology
Dominican Republic	<ul style="list-style-type: none"> • Santo Domingo - Hospital Nacional de Niños Robert Reid
Egypt	<ul style="list-style-type: none"> • Cairo - Pediatric Hemophilia Centre, Ain Shams University • Giza - Shabrawishi Hospital • Mansoura - Mansoura University Children Hospital • Zagazig - pediatrics department, Zagazig University
El Salvador	<ul style="list-style-type: none"> • San Salvador - Hospital Nacional de Niños Benjamin Bloom
Ethiopia	<ul style="list-style-type: none"> • Addis Ababa - Tikur Anbessa Hospital
Ghana	<ul style="list-style-type: none"> • Kumasi - Komfo Anokye Teaching Hospital

Country	City-Clinic
Guinea	<ul style="list-style-type: none"> • Conakry - Hopital National Ignace Deen, CHU de Conakry
India	<ul style="list-style-type: none"> • Aluva - Haemophilia Treatment Centre, District Hospital • Bhopal - Gandhi Medical College • Dibrugarh - Assam Medical College Hemophilia Treatment Center • Kochi - Amrita Institute of Medical Sciences • Ludhiana - Christian Medical College • Manipal - Manipal Academy of Higher Education (MAHE) and Hemophilia Society Manipal Chapter • Noida - Post Graduate Institute of Child Health • Tiruvalla - Believers Church Medical College Hospital
Indonesia	<ul style="list-style-type: none"> • Banjarmasin - Ulin General Hospital
Iran	<ul style="list-style-type: none"> • Ahvaz - Baghaei 2 hospital
Iraq	<ul style="list-style-type: none"> • Baghdad - Hemophilia Center - Medical City • Baghdad - National Center of Hematology - Al-Mustansiriya University • Basra - Basra Center for Hereditary Blood Diseases
Kenya	<ul style="list-style-type: none"> • Eldoret - Moi Teaching and Referral Hospital • Nairobi - Kenyatta National Hospital
Kyrgyzstan	<ul style="list-style-type: none"> • Bishkek - National Center for Maternity and Childhood • Bishkek - National Center of Oncology and Hematology • Osh - Adult Hematology - Osh Interregional Joint Clinical Hospital • Osh - Dept of Pediatric Hematology - Interregional Children's Clinical Hospital
Lesotho	<ul style="list-style-type: none"> • Maseru - Maseru District Hospital Bleeding Disorders Treatment Centre
Madagascar	<ul style="list-style-type: none"> • Antananarivo - CHU Joseph Ravoahangy Andrianavalona (HJRA)
Malawi	<ul style="list-style-type: none"> • Lilongwe - Kamuzu Central Hospital
Malaysia	<ul style="list-style-type: none"> • Alor Setar - Hospital Sultanah Bahiyah • Ampang - Hospital Ampang • George Town - Hospital Pulau Pinang • Ipoh - Hospital Raja Permaisuri Bainun • Johor Bahru - Hospital Sultan Ismail • Johor Bahru - Hospital Sultanah Aminah • Klang - Hospital Tengku Ampuan Rahimah • Kota Bharu - Hospital Raja Perempuan Zainab II • Kota Kinabalu - Hospital Queen Elizabeth • Kota Kinabalu - Hospital Wanita dan Kanak-Kanak Sabah • Kuala Lumpur - Hospital Kuala Lumpur • Kuala Terengganu - Hospital Sultanah Nur Zahirah • Kuantan - Hospital Tengku Ampuan Afzan • Kuching - Hospital Umum Sarawak • Melaka - Hospital Melaka • Seremban - Hospital Tuanku Ja'afar • Taiping - Hospital Taiping
Morocco	<ul style="list-style-type: none"> • Rabat - Adultes - Centre de Référence de l'Hémophilie, Hôpital Ibn Sina • Rabat - Enfants - Centre de Traitement de l'Hémophilie de Rabat, Hôpital d'Enfants de Rabat

Country	City-Clinic
Nepal	<ul style="list-style-type: none"> • Kathmandu - Civil Service Hospital
New Zealand	<ul style="list-style-type: none"> • Christchurch - Christchurch Hospital • Hamilton - Waikato HTC • Palmerston North - Palmerston North hospital
Nigeria	<ul style="list-style-type: none"> • Abuja - National Hospital, Abuja • Benin - University of Benin Teaching Hospital • Enugu State - Southeast HTC, Department of Haematology, UNTH Ituku Ozalla Enugu • Gombe - Gombe State University • Ibadan - University of Ibadan • Kano - Aminu Kano Teaching Hospital • Lagos - Lagos University Teaching Hospital
Norway	<ul style="list-style-type: none"> • Oslo - Oslo university hospital - Haematology department
Pakistan	<ul style="list-style-type: none"> • Karachi - Haemophilia Welfare Society, Karachi • Lahore - Haemophilia Treatment Centre • Peshawar - Haemophilia Welfare Society, Peshawar • Rawalpindi - Haemophilia Treatment Centre
Panama	<ul style="list-style-type: none"> • Panamá City - Hospital del Niño
Philippines	<ul style="list-style-type: none"> • Manila - University of Santo Tomas Hospital
Portugal	<ul style="list-style-type: none"> • Lisbon - Comprehensive Care Centre of Congenital Coagulopathies, Santa Maria Hospital
Senegal	<ul style="list-style-type: none"> • Dakar - Centre National de Transfusion Sanguine
Serbia	<ul style="list-style-type: none"> • Belgrade - Mother and Child Health Care Institute of Serbia "Dr Vukan Cupic"
South Africa	<ul style="list-style-type: none"> • Bloemfontein - University of the Free State • Cape Town - Groote Schuur Haemophilia Comprehensive care centre • Kimberley - Kimberley Hospital
Sudan	<ul style="list-style-type: none"> • Khartoum - Haemophilia Center, Khartoum Teaching Hospital
Syria	<ul style="list-style-type: none"> • Damascus - Syrian Hemophilia Society (SHS)
Thailand	<ul style="list-style-type: none"> • Bangkok - Department of medicine, Siriraj Hospital • Bangkok - Department of medicine, Thammasat University • Bangkok - Department of paediatrics, Chulalongkorn University • Bangkok - Department of paediatrics, Ramathibodi Hospital • Bangkok - Department of paediatrics, Thammasat University • Chiang Mai - Chiang Mai University Hospital • Nakhon Ratchasima - Department of paediatrics, Maharat Nakhon Ratchasima Hospital • Songkla - Department of paediatrics, Prince of Songkla University
Tunisia	<ul style="list-style-type: none"> • Tunis - Hôpital Aziza Othmana
Uganda	<ul style="list-style-type: none"> • Kampala - Mulago Hospital
USA	<ul style="list-style-type: none"> • Winston-Salem - Wake Forest Baptist Health
Venezuela	<ul style="list-style-type: none"> • Caracas - Centro Nacional de Hemofilia - Banco Municipal de Sangre DC
Vietnam	<ul style="list-style-type: none"> • Hanoi - National Children's Hospital • Hanoi - National Institute of Hematology and Blood Transfusion • Ho Chi Minh City - Blood Transfusion Hematology
Zambia	<ul style="list-style-type: none"> • Lusaka - University Teaching Hospital

THANK YOU

TO PWH AND PwVWD

To each PWH and PwVWD enrolled in the WBDR who has kindly agreed to share their data: thank you for helping improve the quality of care for people with bleeding disorders around the world!

TO HTC_s

Thank you to all the dedicated staff at participating hemophilia treatment centres who work hard to ensure that their data meets WBDR data quality standards!

TO OUR PARTNERS

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