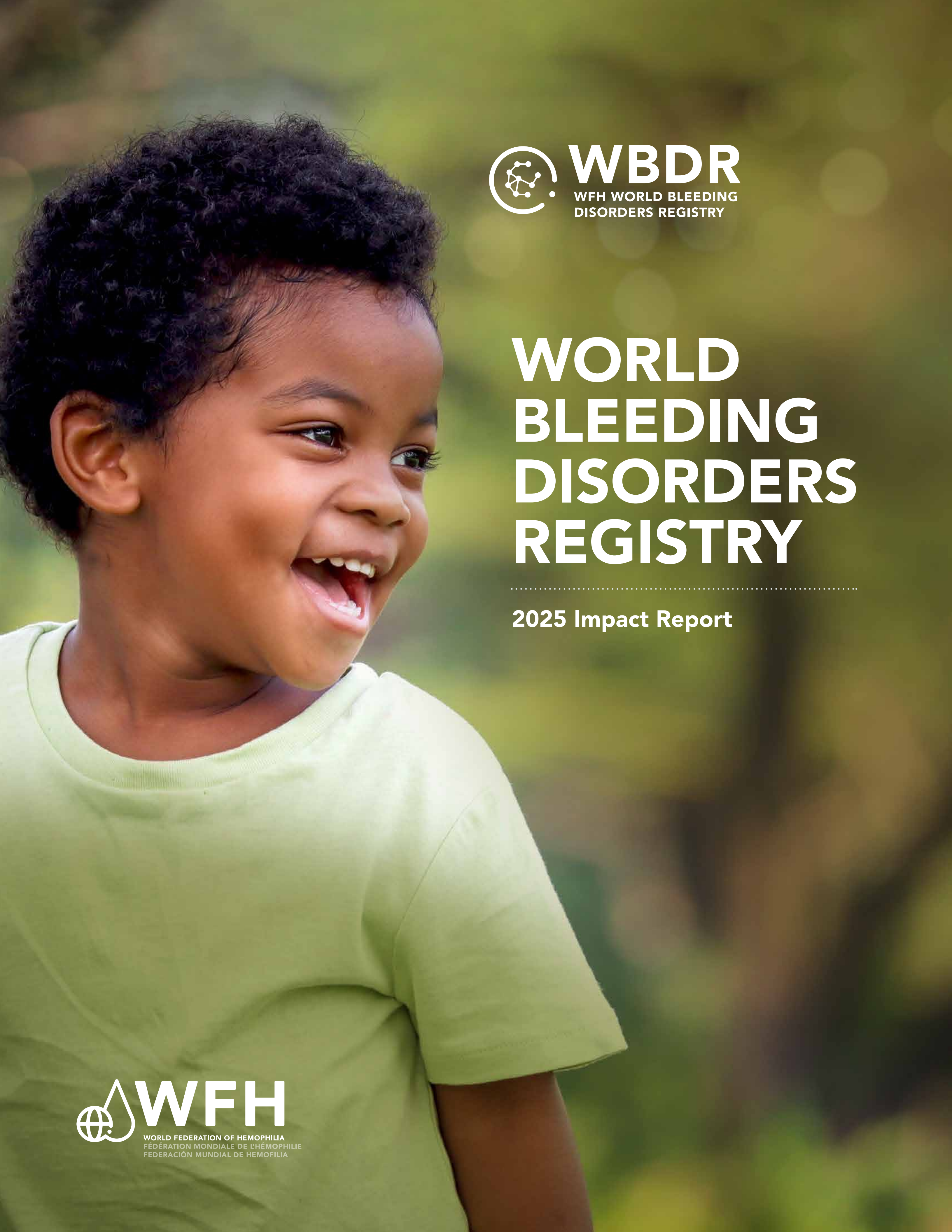

WBDR
WFH WORLD BLEEDING
DISORDERS REGISTRY

WORLD BLEEDING DISORDERS REGISTRY

2025 Impact Report

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

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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.

The WFH works closely with national member organizations (NMOs), healthcare professionals (HCPs), governments, and hemophilia treatment centres to strengthen local health systems and ensure care for people with bleeding disorders is accessible and effective. Through training, education, and practical tools, WFH supports the identification, treatment, and long-term care of people living with bleeding disorders, while promoting global advocacy and collaboration to advance equitable access to care. To learn more, 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 Youttananukorn, PhD

Special thanks to Ticiana Carvalho Pereira, PhD 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 2026

Dear members of the bleeding disorders community: we are pleased to present the 2025 World Bleeding Disorders Registry (WBDR) Impact Report. The WBDR continues to be one of the core initiatives of the World Federation of Hemophilia (WFH), directly supporting research, evidence generation, and global advocacy.

Through the systematic collection of real-world clinical data on people with hemophilia and von Willebrand disease, the WBDR provides a robust and growing evidence base to better understand how bleeding disorders are diagnosed, treated, and managed around the world.

As of December 31, 2025, more than 19,000 people with hemophilia and von Willebrand disease from 131 hemophilia treatment centres across 49 countries have contributed data to the registry. This collective global effort has strengthened understanding of clinical practice patterns, treatment utilization, outcomes, and ongoing disparities in care. By capturing data from all income settings, the WBDR plays a critical role in identifying gaps in access, trends in care, and unmet needs faced by people with bleeding disorders worldwide.

The insights from the WBDR continue to inform research and support improvements in care. The registry serves not only as a research platform, but also as a strategic advocacy tool that enables data-driven decision-making and advancements of equity in care.

This report provides an overview of the WBDR's growth, achievements, and program development over the past year, and highlights its impact on global research and advocacy efforts. With continued collaboration and expansion, the WBDR aims to further establish itself as a global benchmark for understanding bleeding disorders care and measuring progress.

On behalf of the WFH, we extend our sincere appreciation to the healthcare professionals, people with hemophilia, and people with von Willebrand disease who bring this initiative to life. We would also like to recognize our visionary partner who have made it possible for us to develop this registry: Sobi; as well as our collaborating partners: Grifols, Pfizer & Sanofi.

We look forward to continued collaboration as we advance our shared mission of Treatment for All.

Sincerely,

Cesar Garrido
President

Glen Pierce

Glenn Pierce, MD, PhD
Vice President, Medical

ABOUT THE WBDR

The WBDR was launched in 2018 as a platform to collect standardized, real-world data on people with hemophilia and people with VWD. The WBDR is a prospective, longitudinal, observational registry designed to capture individual patient-level data over time, allowing for the development of a dataset that reflects real-world care, treatment patterns, and outcomes across different healthcare settings.

WBDR METHODOLOGY

Hemophilia treatment centres (HTCs) from around the world play a central role in the success of the WBDR by recruiting patients and entering confidential, de-identified data into a secure, web-based data entry system. The WFH works closely with interested HTCs to support participation in the registry, including guidance on ethical and regulatory requirements, Institutional Review Board or ethics committee approvals, patient recruitment, and data management. The WBDR is open to all people with hemophilia and VWD who receive care at a participating HTC. To reduce the risk of selection bias and ensure representative data, HTCs are encouraged to invite all consecutive eligible patients at their centre to enrol. All participants must provide informed consent prior to inclusion in the registry.

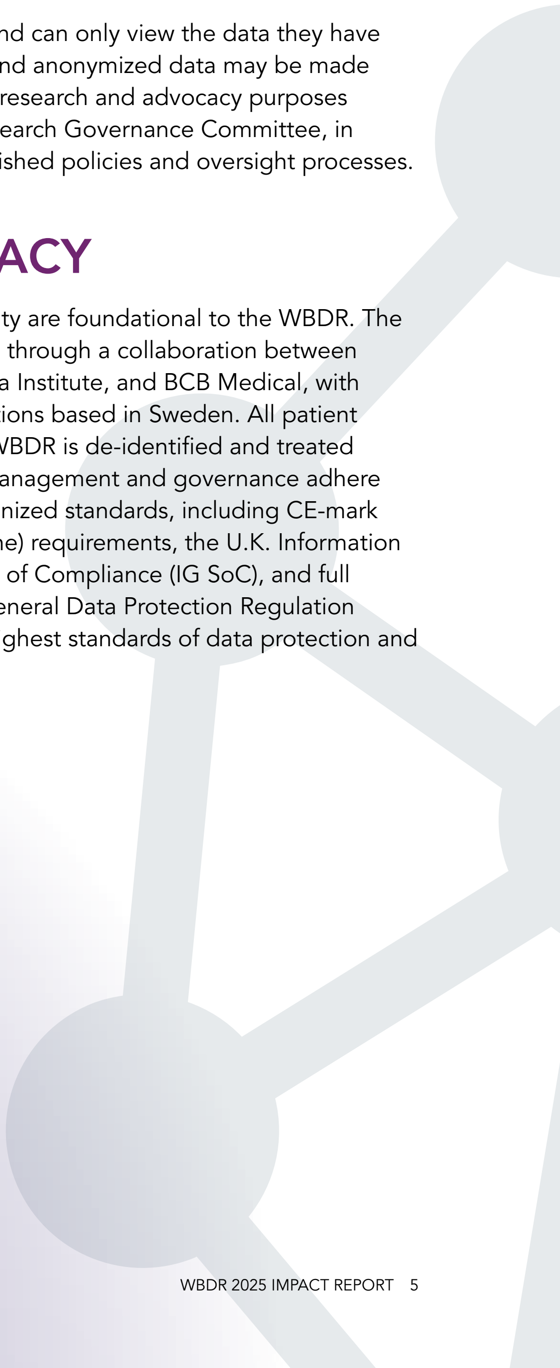
> **The WBDR is open to all people with hemophilia and VWD who receive care at a participating HTC.**

DATA ACCESS AND GOVERNANCE

Each HTC has access and can only view the data they have entered. Aggregated and anonymized data may be made available for approved research and advocacy purposes through the WBDR Research Governance Committee, in accordance with established policies and oversight processes.

DATA PRIVACY

Data privacy and security are foundational to the WBDR. The registry was developed through a collaboration between the WFH, the Karolinska Institute, and BCB Medical, with the latter two organizations based in Sweden. All patient data entered into the WBDR is de-identified and treated as confidential. Data management and governance adhere to internationally recognized standards, including CE-mark (Conformité Européenne) requirements, the U.K. Information Governance Statement of Compliance (IG SoC), and full compliance with the General Data Protection Regulation (GDPR), ensuring the highest standards of data protection and ethical use.



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

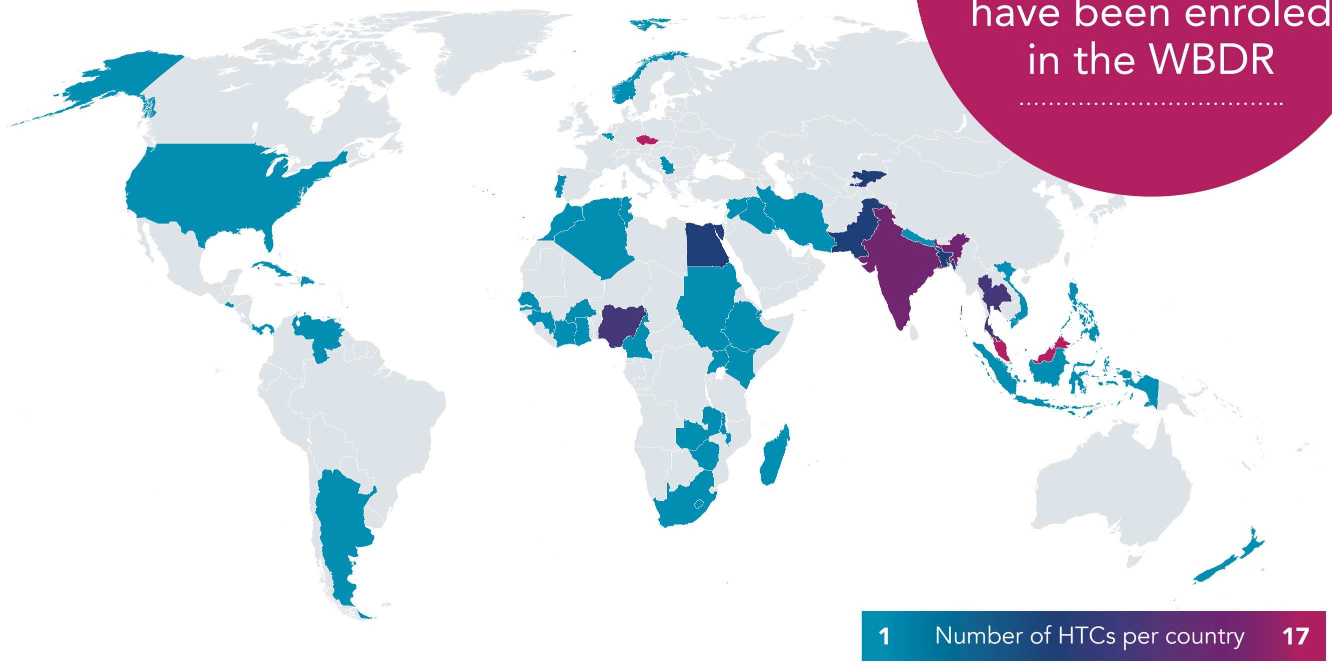
GLOBAL REPRESENTATION IN THE WBDR

19,152

PWH AND PwVWD have been enroled in the WBDR

Figure 1.

COUNTRIES AND HTCs PARTICIPATING IN THE WBDR



Algeria	3
Argentina	2
Bangladesh	6
Barbados	1
Belgium	1
Burkina Faso	1
Cameroon	1
Cuba	1
Czechia	16
Côte d'Ivoire	1
Djibouti	1
Dominican Republic	1
Egypt	4
El Salvador	1
Ethiopia	1
Ghana	1
Guinea	1
India	10
Indonesia	1
Iran	1
Iraq	3
Kenya	2
Kyrgyzstan	4
Lesotho	1
Madagascar	1
Malawi	1
Malaysia	17
Morocco	2
Nepal	1
New Zealand	3
Nigeria	7
Norway	1
Pakistan	5
Panama	1
Philippines	1
Portugal	1
Senegal	1
Serbia	1
South Africa	3
Sudan	1
Syria	1
Thailand	8
Tunisia	1
USA	2
Uganda	1
Venezuela	1
Vietnam	3
Zambia	1
Zimbabwe	1

For a complete list of HTCs, please refer to Appendix 1.

WBDR SINCE 2018

HEMOPHILIA

49 COUNTRIES REPRESENTED

131 HTCs PARTICIPATING

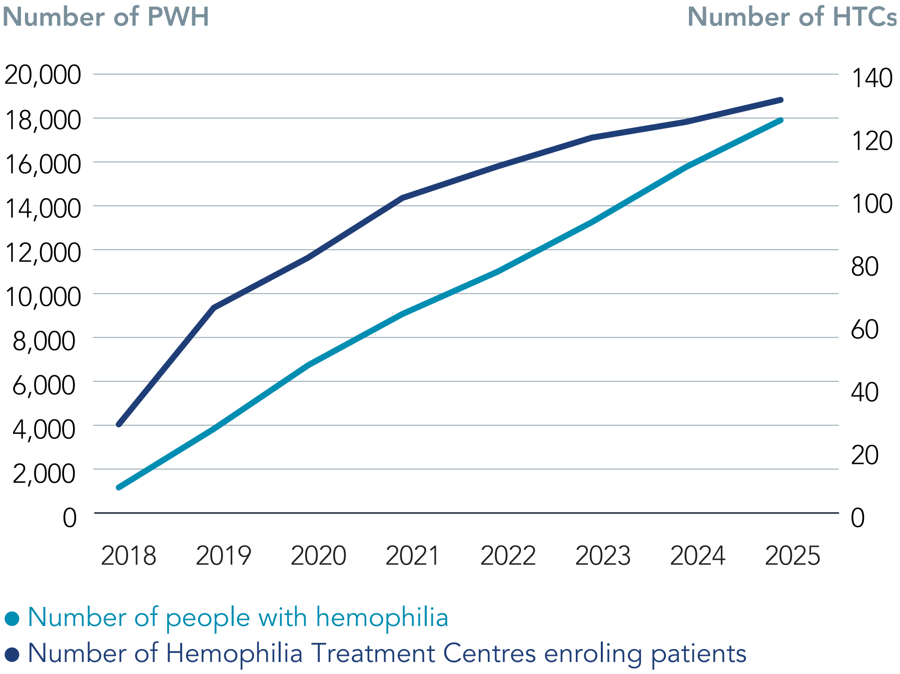
17,196

PEOPLE WITH HEMOPHILIA ENROLED

↑ **12% INCREASE** since 2024

Figure 2.

ENROLMENT CURVE FOR PWH



VON WILLEBRAND DISEASE

25 COUNTRIES REPRESENTED

59 HTCs PARTICIPATING

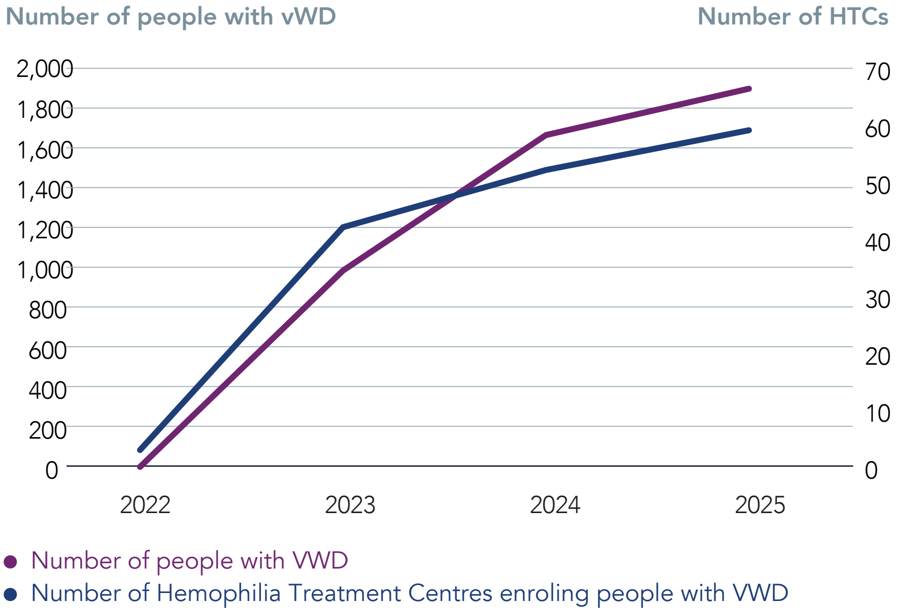
1,893

PEOPLE WITH VWD ENROLED

↑ **14% INCREASE** since 2024

Figure 3.

ENROLMENT CURVE FOR PEOPLE WITH VWD



COLLECTING DATA ON WOMEN AND GIRLS WITH BLEEDING DISORDERS

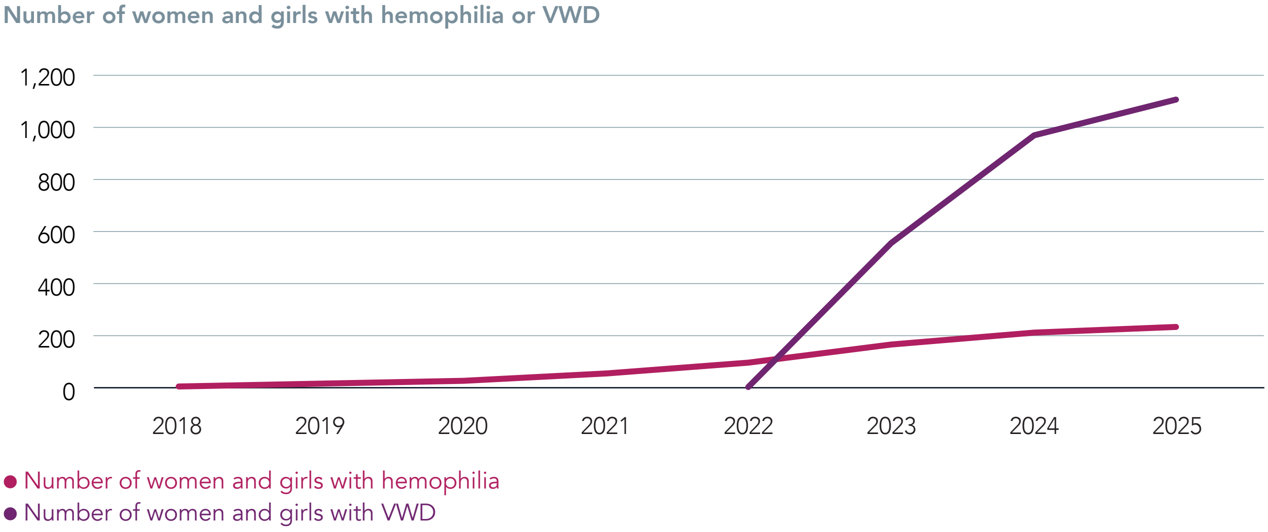
Women and girls with bleeding disorders (WGBD) remain significantly underdiagnosed and underserved globally. Despite experiencing substantial bleeding-related morbidity, bleeding disorders have not been viewed as a condition affecting women and girls, resulting in delayed diagnosis, misdiagnosis, and limited access to appropriate care for women and girls. Symptoms such as heavy menstrual bleeding, postpartum hemorrhage, iron deficiency, and pregnancy-related complications are often normalized or managed symptomatically.

In alignment with WFH strategic priorities, WBDR trainings emphasize how improved data on WGBD directly supports research, informs clinical practice, and strengthens advocacy efforts aimed at improving diagnosis and access to care. To assess the impact of these efforts, enrolment of women and girls with hemophilia and von Willebrand disease is routinely monitored.

In 2025, only a minimal increase was observed in the enrolment of women and girls with hemophilia in the WBDR, underscoring the need for continued efforts to improve representation of this population in global data collection. This focus aligns with the WFH commitment to advancing Treatment for All, regardless of gender, age, geography, or type of bleeding disorder.

Figure 4.

NUMBER OF WOMEN AND GIRLS WITH HEMOPHILIA AND VWD ENROLED IN THE WBDR OVER TIME



WBDR **RESEARCH SUPPORT PROGRAM**

Small Investments, Big Impact: Building Global Research Capacity

The WBDR Research Support Program (RSP) provides funding to selected HTCs worldwide to conduct high-quality research using WBDR data. Through a competitive selection process, awards of $2,000-$5,000 per project support research that generates evidence to inform national policies, improve clinical practices, and advance patient care. Since 2018, the program has supported 59 carefully selected research projects across 25 countries, demonstrating how strategic investments in promising HTCs build sustainable research capabilities that continue producing results long after initial funding ends.

Program Highlights Since 2018

59
Research Projects Funded

25
Countries

42
HTCs Supported

$252,000
USD Awarded

100%
evidence applied to improve policies, practices, and patient outcomes through targeted advocacy

2025 Grant Recipients and Innovative Projects

The WBDR RSP awarded grants to seven HTCs in 2025, focusing on three critical areas of hemophilia and VWD care. **Four projects address musculoskeletal health across South and Southeast Asia**, assessing joint deterioration, bone health, disability burden, and upper limb function in people with hemophilia, helping address key knowledge gaps around long-term complications in resource-limited settings. **Two projects focus specifically on women and girls with bleeding disorders**, investigating prevalence and treatment approaches while improving diagnostic pathways for VWD using WBDR data and shared decision-making tools. **The seventh project monitors real-world prophylaxis outcomes**, tracking how hemophilia and VWD patients respond to preventive treatment in routine clinical practice. Collectively, these projects build evidence in areas frequently underrepresented in clinical trials, such as musculoskeletal complications, women and girls with bleeding disorders, and real-world treatment effectiveness. This directly aligns with the RSP's mission to generate locally driven evidence that supports clinical guidelines and policy decisions.

4
Projects
Musculoskeletal Health

2
Projects
Women & Girls

1
Project
Prophylaxis Monitoring

Alignment with WFH Strategic Priorities

To date, the WBDR RSP directly advances WFH strategic priorities through locally-generated evidence. RSP projects **strengthen early diagnosis** by evaluating age at diagnosis, supporting earlier diagnosis of underrecognized complications such as inhibitors, and helping address critical evidence gaps. Projects **improve care and treatment** by evaluating prophylaxis effectiveness, joint health interventions, and patient education programs in real-world settings. RSP projects **collect, interpret, and disseminate data** through the WBDR, creating standardized evidence that can be compared across countries and care models. All RSP project findings **inform advocacy** at national and international levels to support policy changes, resource allocation, and clinical guideline development. Projects specifically focused on women and girls address VWD diagnosis and female carrier identification—directly **targeting a historically underserved population**. By aligning research investments with WFH priorities, the RSP ensures that every dollar spent generates evidence that moves the global community closer to Treatment for All.

Building Sustainable Research Capacity

Each year, HTCs share success stories on the international stage. HTCs are not only completing funded projects but continuing to generate and disseminate evidence independently, which is a key indicator of sustainable capacity building and local ownership.

Overall, the WBDR RSP not only enhances research capabilities but also strengthens the global bleeding disorders community, bringing attention to critical areas such as early diagnosis, patient education, and data sharing.

By aligning research investments with WFH priorities, the RSP ensures that every dollar spent generates evidence that moves the global community closer to Treatment for All.

WBDR **HTC FUNDING PROGRAM**

Five Years of Strengthening Global Data Equity

Since its inception in 2020, the WBDR HTC Funding Program (HFP) has played a key role in strengthening the capacity of HTCs to collect high-quality, comprehensive, and longitudinal data in the WBDR. Over the past five years, the program has evolved from a foundational capacity-building initiative into a sustained driver of data equity, enabling HTCs in low- and lower-middle-income countries to contribute robust and reliable clinical information to the WBDR, and to the bleeding disorders community at large.

By the end of 2025, 39 HTCs across 22 countries have received support through the program, using funds to improve data entry infrastructure, enhance patient enrolment workflows, strengthen clinical documentation practices, and increase utilization of functional assessments and Quality of Life (QoL) tools.

Advancing Global Data Equity

By supporting HTCs in low resource settings, the HFP has broadened global representation in the WBDR.

Program Reach and Expansion (2020–2025)

From 2020 to 2025, the WBDR HFP has steadily expanded its geographic footprint. Funded HTCs now represent a diverse range of treatment centres across Africa, South-East Asia, Eastern Mediterranean, and South America.

125 Grants

$160,000 Awarded

39 funded HTCs

22 countries

REGION	% of countries who received HFP in each region
Africa	50%
Eastern Mediterranean	27%
South East Asia	18%
Americas	5%

A Closer Look at the Impact of HFP

The impact of the WBDR HFP over the past 5 years can be viewed by assessing the growth in data collection. Table 1 shows the 5-year growth of HTCs who received annual HFP funding to support their data collection. The grants were successfully used to improve the number of patients enroled in the WBDR, therefore improving patient representation. Moreover, longitudinal data capture has significantly improved, as reflected by the increase in follow-up data, better-positioning HTCs to conduct research and publish their work.

Table 1.

Metric	Value	
	n	%
Total Unique Funded HTCs (2021-2025)	39	
HTCs with growth in Patient Enrolment	35	89
HTCs with growth in QoL Assessment	23	59
HTCs with growth in HJHS Assessment (of ever reported HTC*)	14	82
HTCs reaching 35% FUV Threshold (Overall Impact)**	25	64

*17 out of the 39 funded HTCs reported HJHS.

**HTCs achieved the 35% benchmark in at least one of their funding years. The benchmark is defined as HTCs having at least 35% of patients who were enroled by January 1st of a given funding year complete at least one follow-up visit by December of that same year.

HTC-Level Transformations

Since the implementation of the HFP, HTCs have consistently reported concrete advancements in technological capacity, streamlined workflows, enhanced ability to conduct internal analyses and supported patient management.

The Haemophilia Welfare Society HTC in Karachi, Pakistan, has been awarded the WBDR HFP funding annually since 2020.

> **"The WBDR and the HTC Funding Program have transformed our centre from primarily service-based care to structured, data-driven comprehensive care. Beyond financial support, the program has strengthened diagnostic pathways, standardised follow-up, and increased visibility for patients—particularly women and those with severe disease—who are often under-recognised in resource-limited settings."**
>
> – Dr. Munira Borhany, Professor, Consultant Haematologist at Haemophilia Welfare Society HTC, Karachi

Key contributions of the HFP at Haemophilia Welfare Society HTC, Karachi

- Strengthened systematic patient registration and structured data reporting through the WBDR platform.
- Improved standardised bleeding assessment practices.
- Enhanced diagnostic capacity, including more accurate subtype classification of von Willebrand disease and hemophilia.
- Increased patient enrolment and improved follow-up consistency.
- Strengthened monitoring of clinical outcomes, including annual bleeding rate (ABR), treatment patterns, and joint status.
- Enabled monitoring of women and girls presenting with heavy menstrual bleeding and iron deficiency anemia
- Contributed high-quality local data from Pakistan to the global WBDR dataset, enhancing representation from LMICs.
- Successfully used WBDR data to advocate to their local Sindh Government to procure and provide treatment to patients who needed it.

DATA QUALITY ACCREDITATION PROGRAM

Since its launch in 2018, the WBDR Data Quality Accreditation Program (DQA) has ensured that patient-level data is accurate, reliable, and ready to support research, policy, and advocacy. Its main goal is to emphasize the importance of high-quality data within the WBDR and equip HTCs with the essential tools and knowledge needed to achieve and maintain these standards.

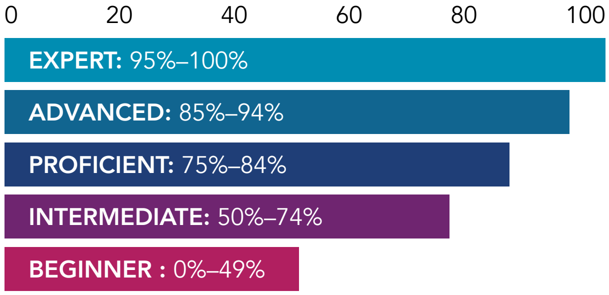
Recognizing that variability in entry practices and local resources is unavoidable, the DQA program mitigates this risk through a robust data cleaning and validation process that:

- **Improves data quality** through regular validation and cleaning.
- **Builds HTC capacity** with targeted data assessments, training, and ongoing support.
- **Provides a clear benchmark** for quality improvement via a scoring system (Fig. 5).
- **Reinforces accountability** through annual data quality reviews.
- **Strengthens registry credibility** as a trusted source of high-quality evidence.

Over the years, WBDR participation has grown nearly fourfold (29 → 108 HTCs), while the number of centres achieving Expert-level data quality (≥95%) has more than tripled (24 → 80). On average, over three quarters of HTCs (77%) consistently meet the highest data quality standards each year (Fig. 6).

Figure 5

WBDR DATA QUALITY SCORING SYSTEM

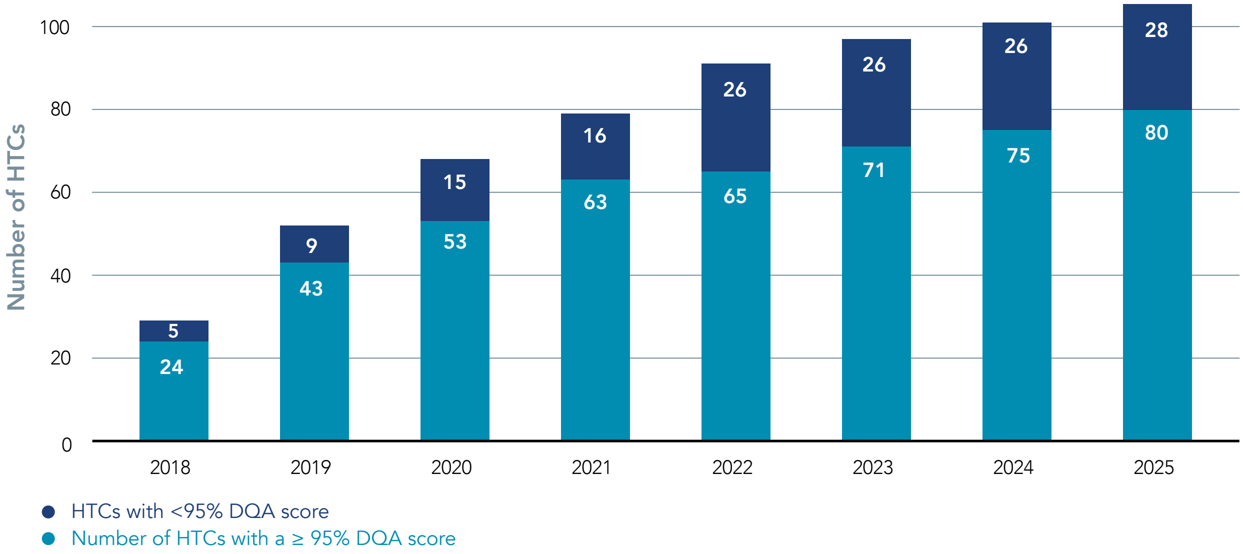


77% of HTCS

Consistently meet the highest data quality standards each year.

Figure 6

NUMBER OF HTCs MEETING THE DQA BENCHMARK (≥ 95%) OVER THE YEARS



WBDR TRAINING AND CAPACITY BUILDING

WBDR 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

In 2025, 95 attendees from over 60 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.

This yearly training is crucial for the improvement of the WBDR program as it strengthens connections between HTCs and the WBDR program, and provides an opportunity to gather constructive feedback from registry users.

HTC training in 2025

25 trainings

40 hours

Eastern Mediterranean data workshop

In November 2025, WFH carried out a two-day regional workshop in Tunis, Tunisia, focused on strengthening the use of data to advance research and advocacy across the Eastern Mediterranean (EM) region. Thirty-four participants from 10 countries, including NMO representatives and healthcare providers from various HTCs were brought together for this event. The workshop addressed disparities in diagnosis, treatment access, and outcomes for people with inherited bleeding disorders in the EM region.

The first day focused on advancing research through better use of data. Participants received practical guidance on research methodology and scientific publishing, with an emphasis on using data from the WFH Annual Global Survey (AGS) and the WBDR for impactful research. Discussions highlighted how national data can identify gaps in care, support funding proposals, and contribute to peer-reviewed publications.

Breakout sessions enabled participants to identify priority research themes relevant to the regional context and explore opportunities for cross-country collaboration.

The second day shifted from research to advocacy. Participants examined how data can inform national policy discussions and strengthen engagement with ministries of health and other decision-makers.

A central component of the workshop was a structured, multi-stakeholder consensus-building exercise designed to identify shared advocacy priorities across the EM region. Participants generated and refined advocacy themes, which were evaluated according to importance, impact, feasibility, and equity using a six-point rating scale. The discussions centred around common regional barriers and strategies for using national data to influence procurement decisions, treatment guidelines, and resource allocation.

This workshop focused on three practical goals:

1. **Expand data and research capabilities** – Enhance the technical expertise of participants with the tools and knowledge to collect, analyze, and use strong data effectively.
2. **Strengthen regional collaboration** – Create space for countries in the region to share experiences, challenges, and solutions, so they can learn from one another.
3. **Improve evidence-based advocacy** – Help participants identify common advocacy priorities and ground them in reliable data, reinforcing the idea that quality evidence is key to overcoming the barriers faced by people with bleeding disorders.

The workshop produced immediate and tangible outcomes. Participants left with improved technical capacity to use data for research and advocacy, clearer regional priorities, and stronger collaboration between clinical and NMO stakeholders. This workshop represents a critical step toward more strategic, data-driven policy engagement and sustained improvements in the lives of people with bleeding disorders.

Immediate Impact

- Clear, stakeholder-defined regional advocacy priorities
- Increased technical capacity to use data for research and policy engagement
- Stronger collaboration between clinicians and NMOs
- A shared roadmap to guide national advocacy and regional coordination

Country training: Bangladesh

Six HTCs in Bangladesh were among the first to join the WBDR in 2018 and 2019. In collaboration with the Hemophilia Society of Bangladesh, the WBDR team delivered a virtual, country-wide workshop to improve HTC participation and patient representation. Healthcare providers from all HTCs in the country as well as NMO members were among the 34 participants.

Following the workshop, the WFH is collaborating with two new HTCs as they work on implementing the WBDR.

Workshop objectives:

1. **Learn about WFH data collection programs** and how to participate
2. **Discover the WBDR** role in research and advocacy in Bangladesh
3. **Introduce the WFH Shared Decision-Making Tool** as a resource for advocacy

FEATURED RESEARCH & PUBLICATION

WBDR: a clinical management tool to drive VWD research in low-resource settings

Over 800 people with VWD have been enrolled from low- and lower-middle-income countries since launching the VWD module in 2023. A WBDR-based study conducted at the Haemophilia Welfare Society HTC in Karachi offered one of the most comprehensive looks at VWD in a low-resource setting.

By using the WBDR as a clinical management tool, the treatment centre was able to systematically assess symptoms, track progress, and tailor care plans based on reliable, standardized data.

The study demonstrates how investment in data and clinical monitoring systems directly translates into better care, even in settings with limited treatment resources. This work helps local clinicians advocate for improved access to treatment and informs global understanding of VWD, ensuring that policies and support programs reflect realworld needs.

Click here to access the publication or scan the QR code

Key Insights:

Most people with VWD had frequent and severe bleeding episodes that significantly interfered with daily life, school attendance, and overall well-being. Common symptoms included gum bleeding, heavy menstrual bleeding, and joint bleeds, all indicating substantial unmet health needs.

Severe forms of VWD—especially Type 3—are far more common in Pakistan than in many other parts of the world. This is linked to genetic factors and limited access to early diagnosis.

Tailored care and data-driven interventions have resulted in fewer bleeding episodes, better mobility and joint health, improved hemoglobin levels, better school/work attendance, and reduced anxiety.

WBDR HTC **ANNUAL STATUS REPORT**

The WBDR HTC Annual Status Report provides HTC-specific data summaries on the enrolment of PWH and PwVWD, treatment data, demographics, and clinical figures.

The HTC Annual Status reports allow healthcare providers to monitor their patient cohorts over time as well as assess overall treatment availability, health outcomes, such as bleeding rates and quality of life, for both research and advocacy purposes.

In response to high interest, the WFH also produces annual country-level reports where there is adequate patient representation in the WBDR. Participating centres can request and share these reports with decision makers, patient advocates, and other community stakeholders in the country.

HTC Annual Status Report

From the WFH
World Bleeding Disorders Registry

January – December **2025**

2025 WBDR Data Summaries

This section includes aggregate and de-identified data from PWH and PwVWD who received care at the HTC and who consented to have their data entered into the WBDR. The tables summarize patient data collected since their enrollment in the WBDR, with specific inclusion criteria, where applicable, described in each subsection. It must be noted that the tables include descriptive statistics of the HTC's PWH and PwVWD population enrolled in the WBDR, and may not be reflective of the larger population of patients registered at HTC. As the proportion of PWH and PwVWD enrolled in the WBDR at the participating HTC increases, the data will become more representative and robust.

Data are reported using frequency distributions and percentages for categorical data, and medians with the interquartile range - quartiles 1 and 3, denoted as IQR, for continuous variables.

People with hemophilia - 2025 Summaries

DEMOGRAPHICS

Table 2: HTC - Demographics summary for PWH

	Mild (>5%) (N=28)	Moderate (1-5%) (N=45)	Severe (<1%) (N=181)	Unknown (N=34)	Total (N=288)
Type of hemophilia, n (%)					
A	26 (93%)	41 (91%)	164 (91%)	32 (94%)	263 (91%)
B	2 (7%)	4 (9%)	17 (9%)	2 (6%)	25 (9%)
Sex, n (%)					
Male	28 (100%)	45 (100%)	181 (100%)	34 (100%)	288
Age of PWH, years					
Median (IQR)	37				
Age by category, n (%)					
Pediatrics (<18 years)	7				
Adults (≥18 years)	2				

CLINICAL DATA - Annualized Bleeding Rate (ABR)

Among the enrolled PWH, ABR analysis includes those who had at least one clinical visit reported in the WBDR in 2025 (N†). ABR was calculated as the number of bleeds reported during visits in 2025, divided by the number of days in the reporting time window (minimum reporting time window was 30 days for inclusion) and annualized by multiplying the result by 365.25. If the interval between the first visit in 2025 and the previous visit was higher than 18 months, the reported bleeds and related time window are disregarded (considered unreliable information). Patients with unknown severity are excluded from the analysis.

Table 6: HTC - ABR summary for PWH, 2025

	Mild (>5%) (N=28)	Moderate (1-5%) (N=45)	Severe (<1%) (N=181)	Total (N=254)
N†	6	13	30	49
ABR, median (IQR)	1 (0, 8)	12 (12, 20)	6 (3, 24)	10 (2, 20)

Table 7: ABR for all PWH in the WBDR with clinical visits in 2025

	Mild (>5%) (N=434)	Moderate (1-5%) (N=1193)	Severe (<1%) (N=2797)	Total (N=4424)
ABR, median (IQR)	2 (0, 6)	5 (2, 10)	5 (2, 12)	4 (2, 10)

Figure 2: Distribution of the ABR for PWH in the WBDR

6

People with VWD - 2025 Summaries

DEMOGRAPHICS

Table 9: HTC - Demographics summary for PwVWD

	VWD (N=185)
Sex, n (%)	
Female	88 (48%)
Male	97 (52%)
Age of PwVWD, years	
Median (IQR)	14 (8, 22)
Age by category, n (%)	
Pediatrics (<18 years)	120 (65%)
Adults (≥18 years)	65 (35%)
VWD Type, n (%)	
Type 1 VWD	37 (20%)
Type 2 VWD	11 (6%)
Type 3 VWD	136 (74%)
Platelet-type VWD	0 (0%)
Unknown	1 (1%)

Figure 3: Distribution of PwVWD at HTC by type

8

* These reports are shared in confidence directly with HTC directors or national registry custodians and are not publicly available.

LOOKING AHEAD
TO 2026

WFH Congress Abstract Presentations

As part of the Research Support Program, and with financial and technical support from the HTC Funding Program, the following abstracts have been accepted for presentation at the 2026 WFH Congress in Kuala Lumpur. These abstracts highlight the growing research capacity of participating HTCs and demonstrate how WBDR data are being translated into locally relevant evidence.

The abstracts reflect collaborative efforts between HTCs and WFH to strengthen data quality, promote analysis of real-world clinical outcomes, and generate insights that inform patient care, and advocacy. Showcasing this work at the WFH Congress not only amplifies the visibility of contributing centres but also reinforces the role of the WBDR as a global platform for evidence generation and knowledge exchange.

Country	Title	Year	Author
Cameroon	Evaluation of the Quality of Life of Hemophiliac Patients Under Prophylactic Treatment in Cameroon	2025	Aurélien Chendjou
Canada	WBDR RSP Series Part 1/6: Beyond Patient Registry – Demonstrating Multifunctional WBDR Value Across Six Domains (32 Research Support Program Projects, 2018–2023)	2025	Toong Youttananukorn
Canada	WBDR RSP Series Part 2/6: Generating Clinical Evidence That Informs Policy – Four Focused Research Areas from 32 RSP Projects (2018–2023)	2025	Toong Youttananukorn
Canada	WBDR RSP Series Part 3/6: Diagnosis Evidence– Findings From Research Projects Under the WFH WBDR Research Support Program (2018–2023)	2025	Toong Youttananukorn
Canada	WBDR RSP Series Part 4/6: Quality-of-Life Evidence – Findings From Research Projects Under the WFH WBDR Research Support Program (2018–2023)	2025	Toong Youttananukorn
Canada	WBDR RSP Series Part 5/6: Prophylaxis Evidence - Findings From Research Projects Under the WFH WBDR Research Support Program (2018–2023)	2025	Toong Youttananukorn
Canada	WBDR RSP Series Part 6/6: Underserved Populations (WGBD/VWD) Evidence - Findings from Research Projects Under the WFH WBDR Research Support Program (2018–2023)	2025	Toong Youttananukorn
Ghana	The Quality of Life of Hemophilia A Patients Accessing Treatment Services	2025	Limmy Sarpong
Indonesia	Level of knowledge of the hemophilia patient's family in the implementation of prophylactic therapy at HTC Ulin Banjarmasin Indonesia	2025	Wulandewi Marhaeni
Madagascar	Prevalence of inhibitor in Malagasy patient with hemophilia	2025	Olivat Rakoto Alson
Malawi	Assessing the change in bleeding rates and related clinical outcomes in haemophilia patients before and after introducing humanitarian aid factor concentrates in Malawi	2025	Francis Mkwenembera
Nepal	Assessment of the Psychosocial (mental health) situation among the PWHs in Nepal	2025	Nripesh Shrestha
Nigeria	Health Related Quality of Life in Haemophiliacs Living in Southern Nigeria and their Care Givers	2025	Omolade Awodu
Pakistan	Capacity Building of Patients to Report Their Bleeds and Treatment Data through myWBDR	2025	Hamza Qureshi
Pakistan	Improving Diagnosis and Treatment of Women with VWD in Pakistan: A Two Phase Analysis Using WBDR Data and Shared Decision-Making Tools	2025	Tahira Zafar

LOOKING AHEAD TO 2026

Partnering with the Japanese Bleeding Disorders Registry

In 2026, the WFH and the Japanese Society on Thrombosis and Hemostasis (JSTH) will finalize the terms of a new collaboration to strengthen global understanding of bleeding disorders through aligned data practices. With the support of WFH, the Japanese Bleeding Disorders Registry (JBDR) has been developed using the WBDR as a benchmark, ensuring data alignment. Under this partnership, JSTH will share patient level data with the WBDR annually, enhancing the WBDR's global patient representation to support evidence informed initiatives aimed at improving care for people with bleeding disorders worldwide.

Global outlook of VWD diagnosis and management through the WBDR

With over 1,800 people with VWD enroled since 2023, the WBDR holds a wealth of data on VWD diagnosis and disease management across 59 HTCs in 25 countries. In collaboration with VWD experts, the WBDR team aims to publish a first-of-its-kind study describing the gaps in diagnostic capacity and identifying critical research areas and evidence-based advocacy priorities for low-resource countries.

Country and HTC Outreach

A series of outreach activities to identify new HTCs to join the WBDR will take place in 2026. Country-specific workshops are planned for countries in South America and South-East Asia. In addition to widening the WBDR reach, these workshops provide training and educational opportunities on the importance of data collection and patient registries for research and advocacy. These workshops will also focus on strengthening participants' ability to translate data into compelling, tailored advocacy messages. This reflects our continued commitment to building regional capacity and ensuring that high-quality data informs decision-making and improves outcomes for the bleeding disorders community.

Appendix 1
LIST OF HTCs

COUNTRY	CITY	CLINIC
Algeria	Annaba	Service d’hématologie CHU Annaba
	Constantine	Unité hémophilie et maladies hémorragiques héréditaires
	Oran	Centre hospitalier universitaire d’Oran
Argentina	Bahía Blanca	CARDHE
	Buenos Aires	Fundación de la Hemofilia and Instituto De Investigaciones Hematológicas “Dr. Mariano R. Castex”
Bangladesh	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	Bridgetown	Queen Elizabeth Hospital
Belgium	Woluwe-Saint-Lambert	Cliniques Universitaires Saint-Luc
Bolivia	Cochabamba	Hospital Clinico Viedma
Burkina Faso	Ouagadougou	CHU Pédiatrique Charles de Gaulles
Cameroon	Yaoundé	CHU Yaoundé
Côte d’Ivoire	Abidjan	CHU de Yopougon
Cuba	Havana	Instituto de Hematología e Inmunología
Czechia	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	IV. Internal and Hematology Dpt.
	Hradec Králové	University Hospital: Dpt. of Pediatric Medicine
	Liberec	Regional Hospital: Dpt. of Clinical Hematology
	Olomouc	University Hospital: Dpt. of Pediatric Medicine
	Olomouc	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

COUNTRY	CITY	CLINIC
Czechia	Ústí nad Labem	Masaryk Hospital: Dpt. of Clinical Hematology
	Ústí nad Labem	Masaryk Hospital: Pediatric Dpt. - Hematology
Djibouti	Djibouti Ville	Service de pédiatrie HGP
Dominican Republic	Santo Domingo	Hospital Nacional de Niños Robert Reid
Egypt	Cairo	Pediatric Hemophilia Centre, Ain Shams University
	Giza	Shabrawishi Hospital
	Mansoura	Mansoura University Children Hospital
	Zagazig	pediatrics department, Zagazig University
El Salvador	San Salvador	Hospital Nacional de Ninos Benjamin Bloom
Ethiopia	Addis Ababa	Tikur Anbessa Hospital
Ghana	Kumasi	Komfo Anokye Teaching Hospital
Guinea	Conakry	Hopital National Ignace Deen, CHU de Conakry
India	Aluva	Haemophilia Treatment Centre, District Hospital
	Bangalore	Victoria Hospital (BMCRI)
	Bhopal	Gandhi Medical College
	Dibrugarh	Assam Medical College Hemophilia Treatment Center
	Hyderabad	Lakshmi Hospital & Research Centre
	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	Banjarmasin	Ulin General Hospital
Iran	Ahvaz	Baghaei 2 hospital
Iraq	Baghdad	Medical City
	Baghdad	Mustansirya University
	Basra	Basra Center for heriditery Blood Diseases
Japan	Tokyo	Ogikubo Hospital
Kenya	Eldoret	Moi Teaching and Referral Hospital
	Nairobi	Kenyatta National Hospital
Kyrgyzstan	Bishkek	National Center for Maternity and Childhood
	Bishkek	National Center of Oncology and Hematology
	Osh	Osh Interregional Joint Clinical Hospital
	Osh	Interregional Children's Clinical Hospital
Lesotho	Maseru	Maseru District Hospital Bleeding Disorders Treatment Centre
Madagascar	Antananarivo	CHU Joseph Ravoahangy Andrianavalona (HJRA)
Malawi	Lilongwe	Kamuzu Central Hospital
Malaysia	Alor Setar	Hospital Sultanah Bahiyah
	Ampang	Hospital Ampang

COUNTRY	CITY	CLINIC
Malaysia	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	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	Rabat	Centre de Référence de l'Hémophilie, Hôpital Ibn Sina
	Rabat	Centre de Traitement de l'hémophilie de Rabat, Hôpital d'Enfants de Rabat
Nepal	Kathmandu	Civil Service Hospital
New Zealand	Christchurch	Christchurch Hospital
	Hamilton	Waikato HTC
	Palmerston North	Palmerston North hospital
Nigeria	Abuja	National Hospital, Abuja
	Benin	University of Benin Teaching Hospital
	Enugu State	South East 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
Pakistan	Karachi	Haemophilia Welfare Society, Karachi
	Lahore	Haemophilia Treatment Centre
	Peshawar	Haemophilia Welfare Society, Peshawar
	Peshawar	Peshawar, Pakistan
	Quetta	Haemophilia Society Children hospital Quetta, Pakistan
	Rawalpindi	Haemophilia Treatment Centre
Panama	Panamá City	Hospital del Niño
Philippines	Manila	University of Santo Tomas Hospital
Portugal	Lisbon	Comprehensive Care Centre of Congenital Coagulopathies, Santa Maria Hospital

COUNTRY	CITY	CLINIC
Senegal	Dakar	Centre National de Transfusion Sanguine
Serbia	Belgrade	Mother and Child Health Care Institute of Serbia "Dr Vukan Cupic"
South Africa	Bloemfontein	University of the Free State
	Cape Town	Groote Schuur Haemophilia Comprehensive care centre
	Kimberley	Kimberley Hospital
Sudan	Khartoum	Haemophilia Center, Khartoum Teaching Hospital
Syria	Damascus	Syrian Hemophilia Society (SHS)
Thailand	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	Tunis	Hôpital Aziza Othmana
Uganda	Kampala	Mulago Hospital
USA	Cincinnati	University of Cincinnati Hemophilia Treatment Center
	Massachusetts	Mass General Brigham
	Winston-Salem	Wake Forest Baptist Health
Venezuela	Caracas	Banco Municipal de Sangre DC
Vietnam	Hanoi	National Children's Hospital
	Hanoi	National Institute of Hematology and Blood Transfusion
	Ho Chi Minh City	Blood Transfusion Hematology
Zambia	Lusaka	University Teaching Hospital
Zimbabwe	Harare	Parirenyatwa Hospital

THANK YOU

TO PWH AND PwVWD

To each PWH and PwVWD enroled 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 HTCs

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

The WFH thanks all of our sponsors for their generous financial support which is allowing us to continue to develop this important initiative.

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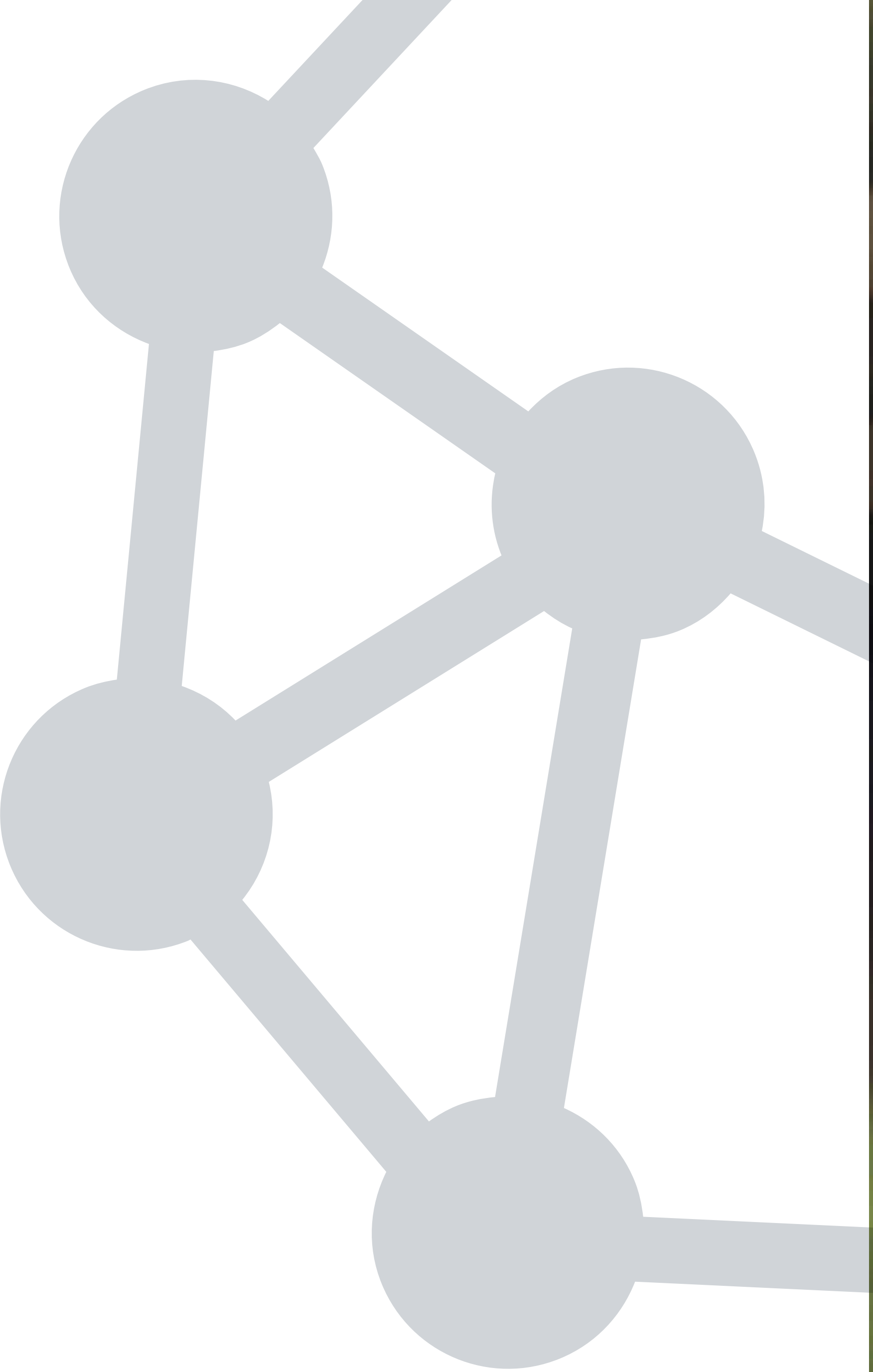

WFH
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