WORLD FEDERATION OF HEMOPHILIA

WORLD BLEEDING DISORDERS REGISTRY

2018 DATA REPORT

WBDR
WFH WORLD BLEEDING DISORDERS REGISTRY

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

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ABOUT THE WFH

For over 50 years, the World Federation of Hemophilia (WFH)—an international not-for-profit organization—has worked to improve the lives of PWH and other inherited bleeding disorders. Established in 1963, it is a global network of patient organizations in 140 countries and has official recognition from the World Health Organization (WHO). To find out more about the WFH, visit www.wfh.org.

THE MISSION OF THE WFH IS TO

IMPROVE AND SUSTAIN CARE FOR PEOPLE WITH INHERITED BLEEDING DISORDERS AROUND THE WORLD.

SOURCE OF DATA

The data presented in the World Bleeding Disorders Registry (WBDR) 2018 Data Report include aggregate and de-identified data from people with hemophilia (PWH) who received care at a participating hemophilia treatment centre (HTC) and who consented to have their data entered into the WBDR.

ACKNOWLEDGEMENTS

To members of the WFH Research & Public Policy department who contributed to the creation of this report:

- Donna Coffin, MSc
- Jennifer Brennan
- Mark Brooker
- Mayss Naccache, MSc
- Ellia Tootoonchian, MPH
- Toong Youttananukorn, PhD

PRESIDENT & VP MEDICAL'S MESSAGE

April 2019

Dear members of the bleeding disorders community,

It is our pleasure to share the 1st World Bleeding Disorders Registry (WBDR) 2018 Data Report with you. This report represents the beginning of a worldwide effort to prospectively capture the real-world clinical experience of people with hemophilia (PWH) from around the globe. It is our hope that these data will serve as a robust tool, supporting research and advocacy initiatives, and pushing the boundaries of care for PWH for many years to come.

2018 was an exceptional first year for the WBDR! By participating in the WBDR, a leading group of 29 hemophilia treatment centres (HTC) and >1,000 PWH have joined our efforts in achieving the World Federation of Hemophilia's (WFH) mission, *Treatment for All*. The aggregate data in this report are based on a minimal set of data, and contributed by the many dedicated health care providers and PWH who are part of this important initiative.

Moving forward into 2019, we are excited to be expanding the WBDR program. Participating HTCs will now have the option of completing an extended data set, including a series of functional and quality of life scales, providing a more complete patient picture; and we expect that many of the HTCs currently in the process of obtaining Institutional Review Board approval will be joining the WBDR over the next several months. The development of the WBDR also includes an international data integration component, with the aim of transferring data from existing hemophilia registries, directly into the WBDR. A proof of concept study is currently underway with the Czech Republic National Registry. This project will be extended to additional hemophilia registries in 2019. It is only with international collaboration between countries, HTCs and PWH, that we can gather enough quality data to conduct global comparative analyses of care provided and outcomes achieved in rare disorders, such as hemophilia.

On behalf of the WFH, we warmly thank all of our participating HTCs and PWH, whose enthusiasm and dedication to both this patient registry and to improving the care for PWH, have allowed the WBDR to be established. The initial success and reach of the WBDR have laid a solid foundation on which we will continue to expand in 2019, and beyond.

Sincerely,

Alain Weill
President

Glenn Pierce
VP Medical

ABOUT THE WBDR

Launched in January 2018, the WBDR provides a platform for HTCs around the world to collect standardized data on PWH. The WBDR is a prospective, longitudinal, observational registry of patients diagnosed with hemophilia A and B. It is a privacy-protected web-based data entry system, that allows for the collection of individual patient data, thus providing a clinical profile for each PWH.

THE WBDR IS OPEN TO
ALL PEOPLE WITH

HEMOPHILIA A OR B

ALL SEVERITIES, WHO ARE A PATIENT AT A PARTICIPATING HTC.

WBDR METHODOLOGY

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

The WBDR is open to all people with hemophilia A or B (all severities) who are a patient at a participating HTC. The HTCs are asked to invite all consecutive hemophilia A and B patients at their clinic to enroll in the WBDR in order to minimize the risk of selection bias. All PWH who agree to participate must provide consent.

IMPLEMENTATION

Implementation of the WBDR begins with the HTCs. Candidate HTCs are identified, with the help of our National Member Organizations (NMO), and invited to register with the WBDR, directly by the WBDR team. Interested HTCs can also express their interest in participating by completing the WBDR application form online or by emailing the WBDR team at wbdr@wfh.org. The WBDR team is available to assist HTCs in obtaining ethical approval from their local organization.

INSTITUTIONAL REVIEW BOARDS/ ETHICS COMMITTEE

Hemophilia treatment centres must obtain Institutional Research Board or Ethics Committee approval from their local institution prior to enrolling PWH into the WBDR. All WBDR documents required for ethics submission are provided to HTCs, and translated versions are available upon request.

CONSENT

People with hemophilia who are interested in participating in the WBDR must be a patient at a participating HTC and must provide informed consent to have their confidential and de-identified data entered into the registry. If a PWH decides not to participate, they will continue to receive the same care as all other PWH at their HTC. For PWH who decide to participate in the WBDR, the treatment team of the HTC will record patient data after each clinic visit, and will enter it into the WBDR.

COLLECTION OF DATA AND FOLLOW-UP VISITS

Patient data are collected at the baseline visit (the visit PWH provide informed consent) and at all subsequent follow-up clinic visits. At the baseline visit, retrospective data based on the previous six months is collected. At each subsequent follow-up visit, data for the period since the previous clinic visit is collected. This method ensures that all data and events over the course of time are captured.

2018 DATA: MINIMAL DATA SET

The data collected in the WBDR in 2018 is based on a minimal data set (MDS) (see Appendix 2). An extended data set (EDS) has been developed and was implemented in February 2019. These data will appear in future WBDR Data Reports.

UNIQUE PATIENT IDENTIFIER

Using a cryptographic hashing process, all PWH entered into the WBDR are provided a unique patient identifier (UPI). The UPI reduces the risk of duplicate patients being entered into the WBDR and will be useful for linking with other databases in the future. For more information on the UPI and the cryptographic process, please see the WBDR Data Privacy & Security document (www.wfh.org/en/our-work/wbdr/data-privacy).

TRANSFER PATIENTS

Patients can be transferred between participating HTCs within the WBDR. This transfer function is useful in countries where PWH receive care at more than one HTC.

DATA LINKAGE

The WBDR includes an international data integration component, whereby existing hemophilia registries can import their data directly into the WBDR and become part of this international registry. Please see page 34 for more information.

DATA QUALITY

The WBDR Data Quality Accreditation program is designed to enhance the completeness, accuracy and consistency of the data entered in the WBDR. The WBDR team works closely with all HTCs to ensure their data meets the WBDR data quality standards. Please see page 32 for more information on the WBDR data quality program.

DATA ACCESS AND GOVERNANCE

Each HTC has access to the data they enter into the WBDR, but they cannot view data that is entered from any other HTC and no other HTC can view their data. Every year, aggregate data from all enrolling HTCs will be published in the WBDR Annual Data Report. Access to data for research and advocacy purposes will be available through the WBDR Data Governance Committee.

DATA PRIVACY

The WBDR database was developed through collaborative efforts of the WFH, the Karolinska Institute, and Health Solutions—the latter two organizations based in Sweden. All patient information entered in the WBDR is de-identified and confidential. Data policy guidelines of Health Solutions adhere to the CE-mark (Conformité Européenne) and the U.K. standard IGSoC (Information Governance Statement of Compliance), and are compliant with the General Data Protection Regulation, which were enforced in the European Union as of May 25, 2018. Please see the WBDR Data Privacy & Security document for more information (https://www.wfh.org/en/our-work/wbdr/data-privacy).

HTC SUPPORT AND TRAINING PROGRAM

The WBDR support and training program is available to all participating HTCs. It was developed to ensure long-term success of the WBDR. In-person and webinar trainings are available on:

- Ethics submission process
- Obtaining informed consent
- Data collection
- WBDR datasets
- Data quality management
- Using data effectively for research and advocacy purposes

WBDR investigator meetings and in-country data collection workshops are conducted throughout the year.

OVERALL, IN 2018, NEARLY

50 HOURS OF TRAINING

WERE PROVIDED **TO 39 HTCs.**

ABOUT THE WBDR 2018 DATA REPORT

The data in the first WBDR Data Report includes patient data collected between the launch date of January 26, 2018 and December 31, 2018. These data stem from 29 participating HTCs, representing 19 countries, who received ethical approval from their local organization and enrolled at least one PWH into the WBDR, during 2018. The data represent 1,181 PWH who provided informed consent to participate in the WBDR. At the time of publication of this Data Report (April 2019), an additional 20 HTCs are participating in the WBDR, for a total of 51 HTCs from 31 countries (see Appendix 1).

Please note, that at data cut-off for this report (December 31, 2018), it is possible that not all eligible PWH at participating HTCs had been invited to join the WBDR. Therefore, the data in this report may not represent the entire patient population at each HTC, limiting generalizability. As the proportion of PWH enrolled in the WBDR at participating HTCs increases, the data will become more reflective of the patient population at each HTC.

The 2018 WBDR data are reported using frequency distributions and percentages for categorical data, and medians with quartiles 1 and 3, denoted as (Q1–Q3), for continuous variables.

WFH WBDR STEERING COMMITTEE

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

- Barbara Konkle, MD, Co-Chair
- Alfonso Iorio, MD, Co-Chair
- Vanessa Byams, DrPH
- Saliou Diop, MD
- Cedric Hermans, MD
- Declan Noone, MSc
- Jamie O'Hara, MSc
- Glenn Pierce, MD, PhD, VP Medical WFH
- Marijke van den Berg, MD, PhD
- Alain Weill, President WFH

The WFH would also like to thank previous members of the WFH Research, Epidemiological and WBDR committees, whose dedication and hard work have also contributed to the development and success of the WBDR:

- Paula Bolton-Maggs, MD
- Susan Cutter, MSW, MPA
- Donna DiMichele, MD
- Rob Hollingsworth, PhD
- Nigel Key, MD
- Adolfo Llinás, MD
- David Lillicrap, MD
- Margareth Castro Ozelo, MD
- Flora Peyvandi, MD, PhD
- Mike Soucie, PhD
- Alok Srivastava, MD
- Craig Upshaw
- Deon York
- Jerzy Windyga, MD, PhD

SUMMARY DATA OF THE WBDR, 2018

19
COUNTRIES

29
HEMOPHILIA TREATMENT CENTRES

1,181
PEOPLE WITH HEMOPHILIA

TABLE 1

DATA INCLUDED IN THE WBDR 2018 DATA REPORT

People with hemophilia, n	1,181
Hemophilia treatment centres*, n	29
Countries, n	19
Distribution of PWH by region†	
Africa	111 (9.4%)
Americas	180 (15.2%)
Eastern Mediterranean	402 (34.0%)
Europe	65 (5.5%)
South-East Asia	294 (24.9%)
Western Pacific	129 (10.9%)
Distribution of PWH by GNI‡	
High income	215 (18.2%)
Upper middle income	363 (30.7%)
Lower middle income	396 (33.5%)
Low income	207 (17.5%)

* HTCs included are those who had ethical approval and enrolled at least one PWH in 2018
† Regional distribution based on the World Health Organization (WHO) regional groupings[2]
‡ Gross National Income categories based on The World Bank Group 2017 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)"[3]

TABLE 2

DEMOGRAPHICS

Type of hemophilia, n (%)	All PWH (n = 1,181)
Hemophilia A	997 (84.4%)
Hemophilia B	179 (15.2%)
Unknown	5 (<1%)
Severity*, n (%)	
Mild	156 (13.2%)
Moderate	362 (30.7%)
Severe	605 (51.2%)
Unknown	58 (4.9%)
Sex, n (%)	
Male	1,178 (>99%)
Female	3 (<1%)
Age of PWH†	
Age, years, median (IQR)	16 (8–28)
Pediatrics (<18 years), n (%)	628 (53.2%)
Adults (≥18 years), n (%)	553 (46.8%)

IQR = interquartile range
* Severity defined by factor level: severe, ≤0.01 international units (IU); moderate, 0.01–0.05 IU; mild, >0.05 IU
† Age of PWH was calculated as of December 31, 2018

TABLE 3

DIAGNOSIS AND CLINICAL HISTORY

	All PWH (n = 1,181)	Severe PWH (n = 605)
Age at diagnosis, months, median (IQR)	17 (6–75)	11 (5–34)
By age category, n (%)		
0–12 months	473 (40.1%)	265 (43.8%)
1–4 years	355 (30.1%)	206 (34.1%)
5–17 years	243 (20.6%)	97 (16.0%)
18–44 years	98 (8.3%)	31 (5.1%)
45+ years	11 (<1%)	5 (<1%)
Age unknown	1 (<1%)	1 (<1%)
Newly diagnosed PWH in 2018, n (%)	65 (5.5%)	22 (3.6%)
Age at first bleed*, months, median (IQR)	8 (5–18)	7 (4–12)
Age at first joint bleed†, months, median (IQR)	24 (12–53)	21 (12–43)

IQR = interquartile range
* Based on 1,134 PWH with data on first bleed (All PWH) and 582 for severe PWH.
† Based on 951 PWH with data on first joint bleed (All PWH) and 496 for severe PWH.

TABLE 4

CLINICAL DATA

	All PWH (n = 1,176*)	Severe PWH (n = 604*)
Total bleeding events, n	6,680	3,244
Location of bleed, n (%)		
Joint	4,965 (74.3%)	2,521 (77.7%)
Muscle	1,040 (15.6%)	424 (13.1%)
Central nervous system	28 (<1%)	10 (<1%)
Other location	636 (9.5%)	287 (8.8%)
Not reported	11 (<1%)	2 (<1%)
Annualized bleeding rates†, median (IQR)		
Annualized bleeding rate (ABR)	6 (2–16)	6 (2–14)
Annualized joint bleeding rate (AJBR)	8 (4–18)	8 (4–16)
Target joints‡, n (%)		
≥1	712 (60.6%)	386 (63.9%)
Inhibitors, n (%)		
Not tested§	747 (65.4%)	313 (52.4%)
Tested§	395 (34.6%)	284 (47.6%)
Diagnosed with an inhibitor	49 (12.4%)	42 (14.8%)
Not diagnosed with an inhibitor	346 (87.6%)	242 (85.2%)
Titers of confirmed inhibitor ‖		
Low-titer inhibitor	9 (18.4%)	7 (16.7%)
High-titer inhibitor	33 (67.3%)	30 (71.4%)
Unknown titer (e.g. mixing study)	7 (14.3%)	5 (11.9%)

CONT'D

CLINICAL DATA

	All PWH (n = 1,176*)	Severe PWH (n = 604*)
Hospitalizations		
Number of unique PWH hospitalized, n (%)	249 (21.2%)	98 (16.2%)
Total hospitalizations, n	587	296
Days per hospitalization, median (IQR)	4 (3–6)	4 (2–5)
Reason for hospitalizations, n (%)		
Joint bleed	352 (60.0%)	197 (66.6%)
Surgery	27 (4.6%)	14 (4.7%)
Soft tissue bleed	23 (3.9%)	7 (2.4%)
Iliopsoas muscle bleed	17 (2.9%)	9 (3.0%)
Intracranial hemorrhage	8 (1.4%)	4 (1.4%)
Thromboembolic event	2 (<1%)	0 (0%)
Other bleed	54 (9.2%)	20 (6.8%)
Other muscle bleed	41 (7.0%)	16 (5.4%)
Other	63 (10.7%)	29 (9.8%)

IQR = interquartile range

* Missing data on five PWH, including one severe PWH

† Annualized bleeding rate (ABR) is defined as the sum of bleeds at baseline visit (six months of retrospective data) annualized. Annualized joint bleeding rate (ABJR) is defined as the sum of joint bleeds at baseline visit, annualized. AJBR data are based on 792 PWH and 404 severe PWH who reported at least one joint bleed

‡ Includes PWH who reported at least one target joint in 2018. Target joints are defined as 'three or more spontaneous bleeds into a single joint within a consecutive 6-month period. Where there have been ≤2 bleeds into the joint within a consecutive 12-month period the joint is no longer considered a target joint'[1]

§ Inhibitor data are based on 1,142 PWH. PWH who never received treatment were removed from this analysis. Testing methods include Bethesda, Nijmegen-Bethesda, and mixing study (activated partial thromboplastin time)

‖ The cut-off value for the presence of inhibitors is defined as a titer ≥0.6 Bethesda units (BU); low-titer inhibitors are defined as <5 BU; high-titer inhibitors are defined as ≥5 BU[1]

** Hospitalization is defined as spending at least one overnight in the hospital

TABLE 5

TREATMENT DATA

	All PWH (n = 1,181)	Severe PWH (n = 605)
Treatment		
Received at least one treatment in 2018, n (%)	975 (82.6%)	553 (91.4%)
Did not receive treatment in 2018, n (%)	206 (17.4%)	52 (8.6%)
TREATMENT INDICATION*		
Hemophilia A, n	833†	491
Indications, n (%)		
On-demand	635 (76.2%)	333 (67.8%)
Prophylaxis	318 (38.2%)	265 (54.0%)
Surgery	13 (1.6%)	6 (1.2%)
Trauma with no known bleed	9 (1.1%)	6 (1.2%)
Immune tolerance induction	8 (1.0%)	8 (1.6%)
Selective prevention of bleed (i.e. before activity)	7 (<1%)	6 (1.2%)
Other	21 (2.5%)	11 (2.2%)
Hemophilia B, n	139	62
Indications, n (%)		
On-demand	109 (78.4%)	40 (64.5%)
Prophylaxis	46 (33.1%)	36 (58.1%)
Surgery	4 (2.9%)	2 (3.2%)
Trauma with no known bleed	1 (<1%)	0 (0%)
Selective prevention of bleed (i.e. before activity)	1 (<1%)	0 (0%)

The WBDR is a simple and excellent tool that allows for better statistical knowledge of different variables of the population followed by the centre. The process was simple and easy to implement. It also allows collaboration with local and global statistics.

— Daniela Neme, MD & Mariano R. Castex, MD
Fundación de la Hemofilia and Instituto De Investigaciones Hematológicas, Buenos Aires, Argentina

CONT'D

TREATMENT DATA

	All PWH (n = 1,181)	Severe PWH (n = 605)
TREATMENT TYPE*		
Hemophilia A, n	833†	491
Treatment type, n (%)		
FVIII, standard half-life	581 (69.7%)	395 (80.4%)
FVIII, extended half-life	198 (23.8%)	48 (9.8%)
Cryoprecipitate	58 (7.0%)	25 (5.1%)
Bypassing agent	36 (4.3%)	34 (6.9%)
Plasma	22 (2.6%)	6 (1.2%)
Other	22 (2.6%)	13 (2.6%)
Hemophilia B, n	139	62
Treatment type, n (%)		
FIX, standard half-life	88 (63.3%)	53 (85.5%)
FIX, extended half-life	36 (25.9%)	10 (16.1%)
Plasma	14 (10.1%)	4 (6.5%)
Other	24 (17.3%)	5 (8.1%)

* Number of unique PWH in whom at least one treatment indication and at least one treatment type were reported in 2018. Total percentage can exceed 100% since a PWH may be counted in more than one indication category and for more than one treatment type

† Number of patients with hemophilia A who received at least one treatment in 2018. Three PWH with hemophilia type unknown were excluded

TABLE 6

MORTALITY DATA

	All PWH (n = 1,181)	Severe PWH (n = 605)
Deaths, n (%)		
Total deaths	3 (<1%)	3 (<1%)
Attributed to hemophilia	3 (100%)	3 (100%)
Not attributed to hemophilia	0 (0%)	0 (0%)
Cause of death		
Intracranial hemorrhage	2 (67%)	2 (67%)
Bleed (excluding intracranial)	1 (33%)	1 (33%)

GLOBAL REPRESENTATION IN THE WBDR, 2018

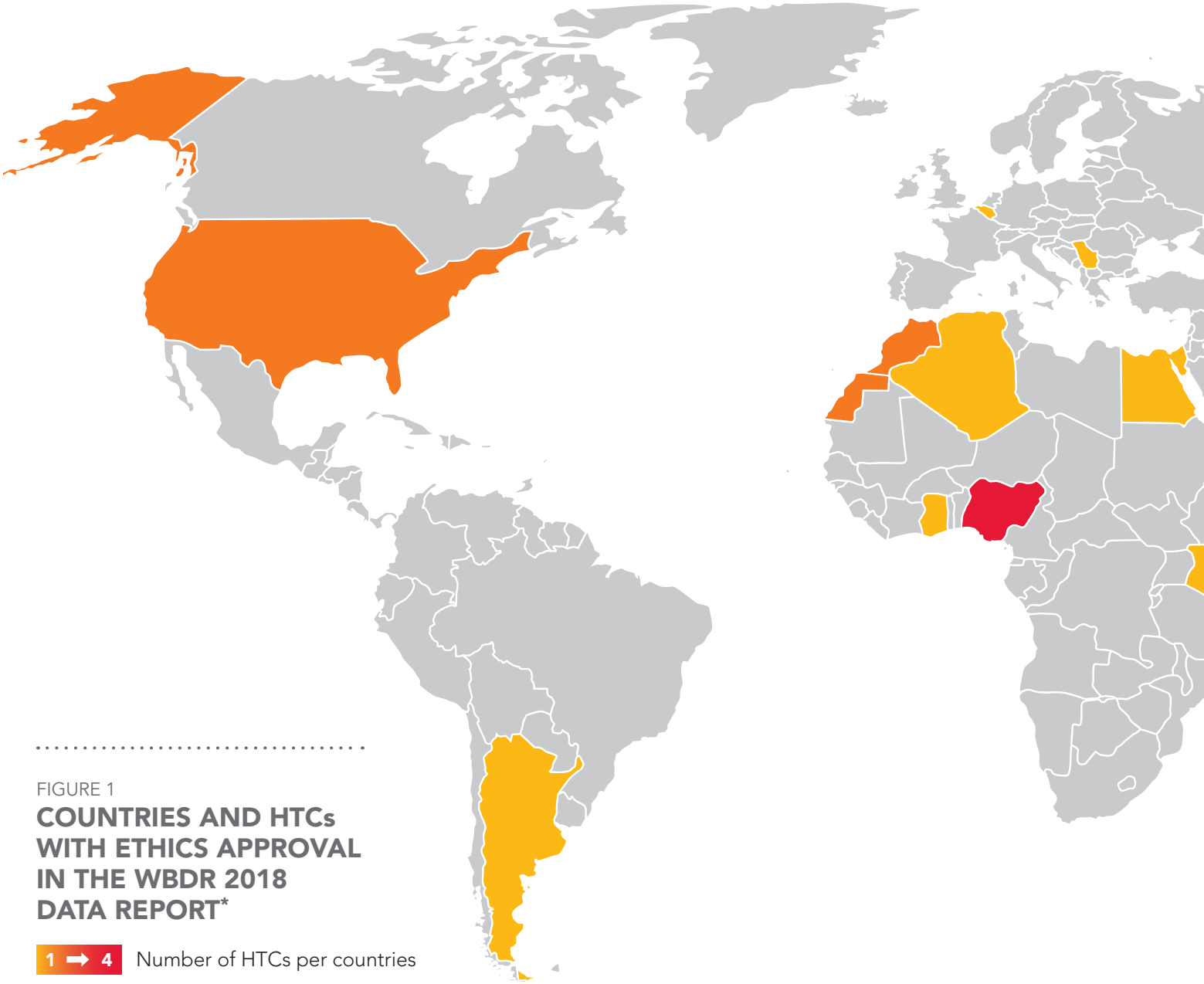


FIGURE 1

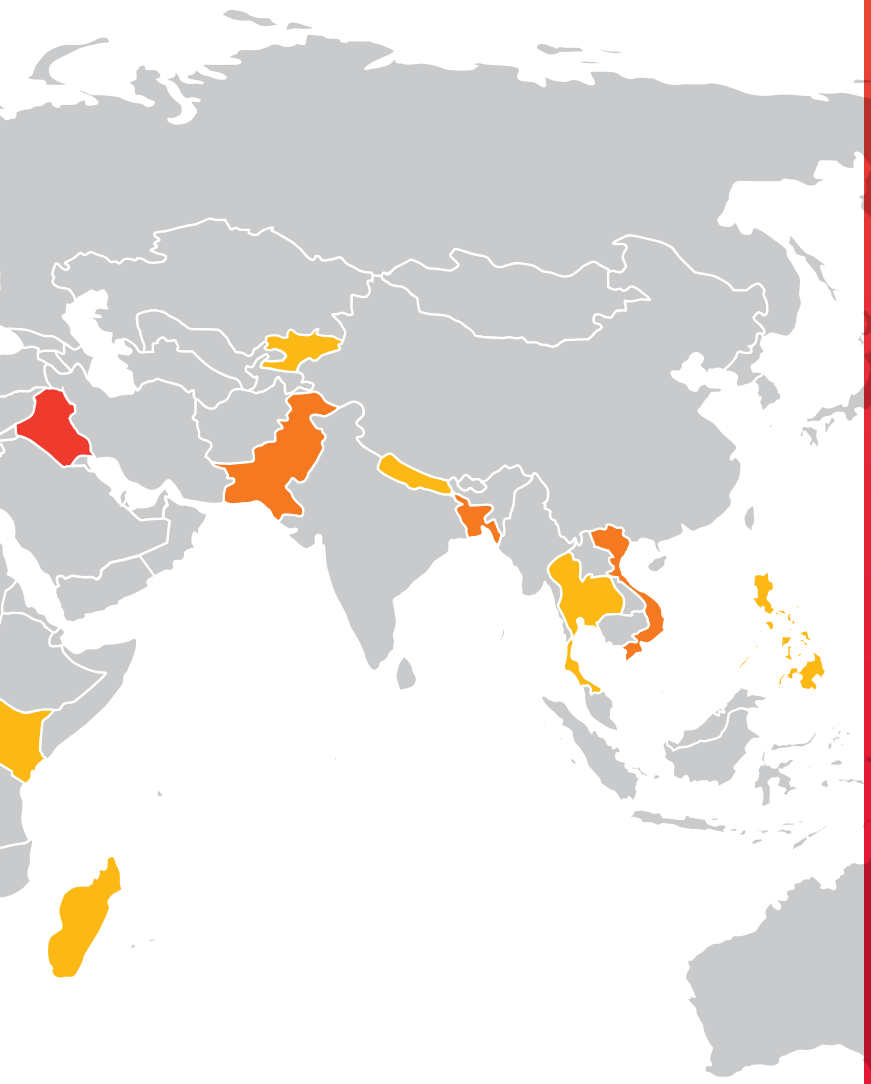
COUNTRIES AND HTCs WITH ETHICS APPROVAL IN THE WBDR 2018 DATA REPORT*

1 → 4 Number of HTCs per countries

* Please see Appendix 1 for HTC and country participation as of April 2019.

The WBDR is a unique approach to making each patient count. Each one of us, and all of us together, can better understand, treat, and cure hemophilia around the world through the WBDR.

— Cedric Hermans, MD
WFH Board of Directors



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VIETNAM
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National Institute of Hematology and Blood Transfusion, Hanoi

DATA INCLUDED IN THE WBDR 2018 DATA REPORT

PARTICIPATION

In 2018, a total of 1,181 PWH were enrolled in the WBDR, representing six regions, 19 countries and 29 HTCs (Figures 1 and 2).

The regional classification used in the WBDR is based on the WHO regional classification[2]. The majority of PWH are from the Eastern Mediterranean region (Algeria, Egypt, Iraq, Morocco, Pakistan) and the South-East Asia region (Bangladesh, Nepal, Thailand), representing 34% and 25% of PWH, respectively (Figure 3).

The distribution of participants by Gross National Income (GNI) per capita[3], demonstrates that approximately one third of the participant PWH are from lower middle income countries (33%), another third from upper middle income countries (31%), and the final third is split between low (18%) and high (18%) income countries (Figure 4).

FIGURE 2

PWH AND HTC ENROLLMENT IN THE WBDR

JANUARY 2018 TO APRIL 2019

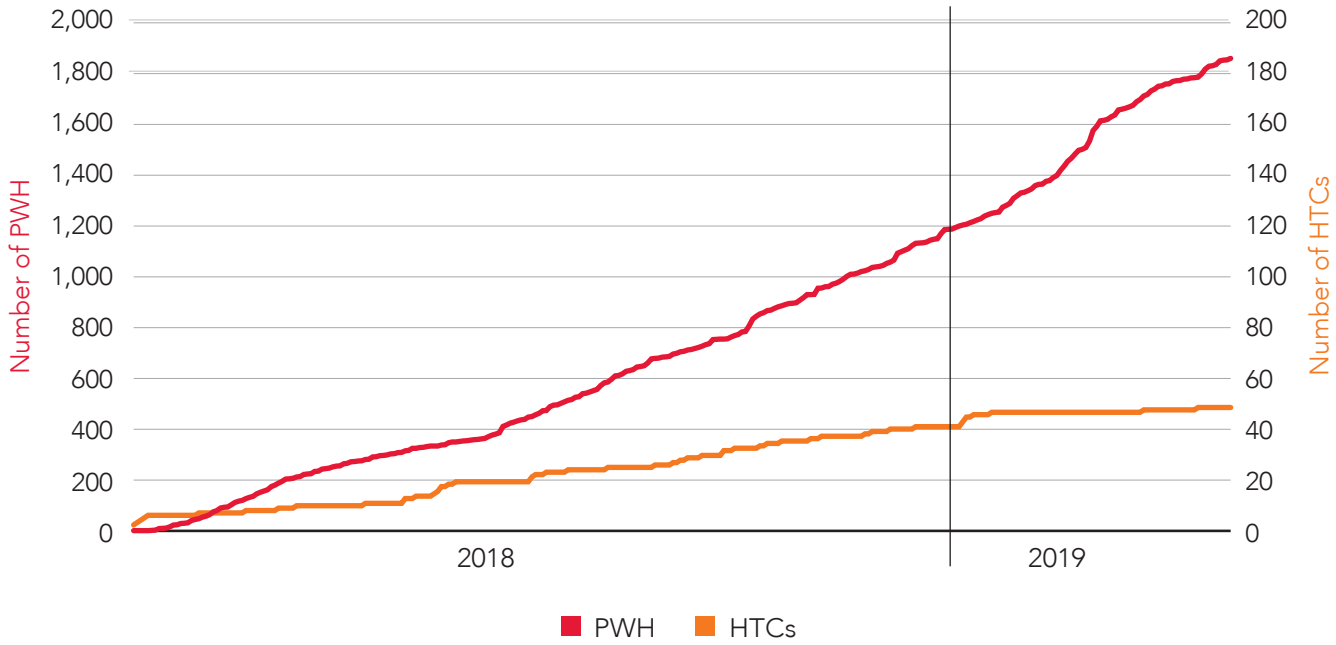


FIGURE 3

DISTRIBUTION OF PWH BY REGION

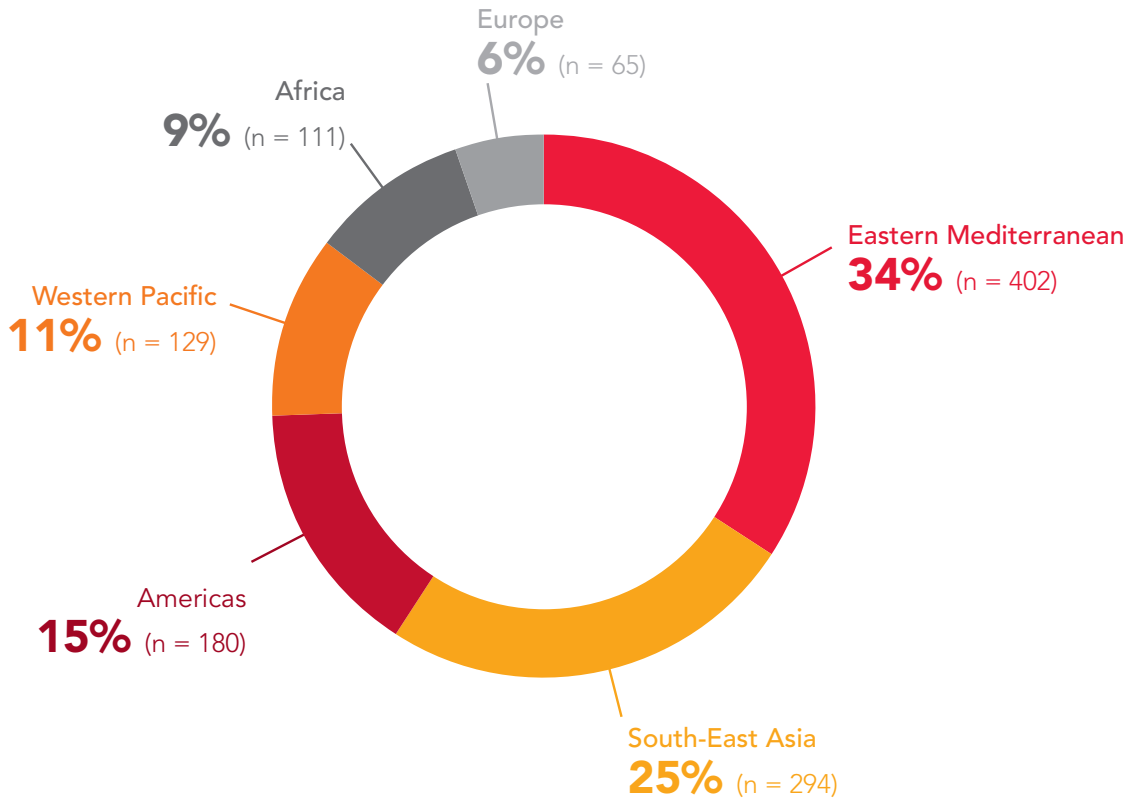
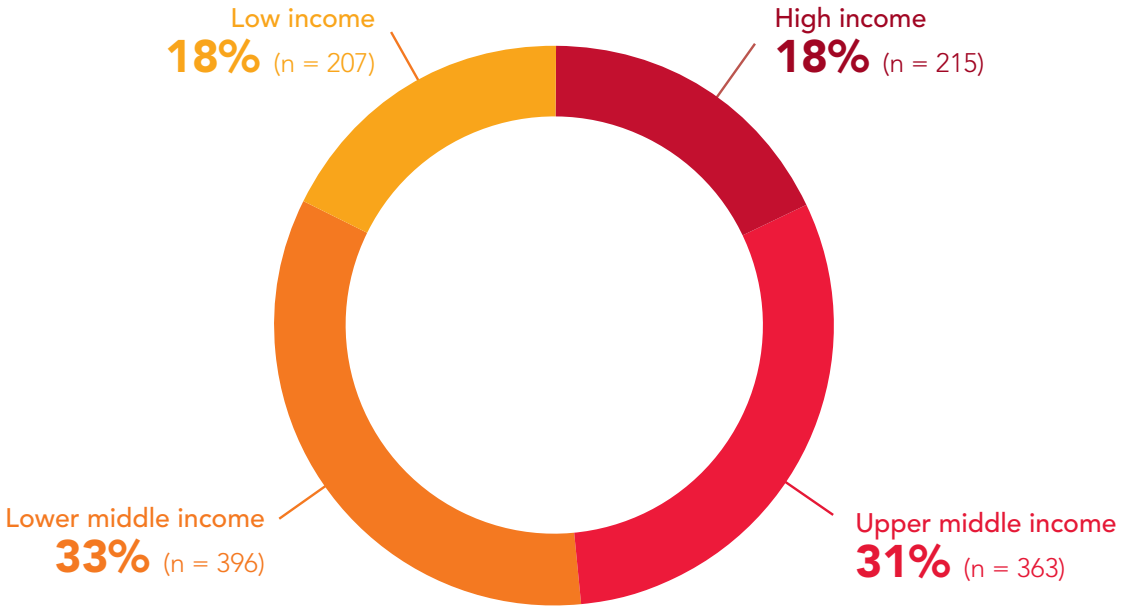


FIGURE 4

DISTRIBUTION OF PWH BY GROSS NATIONAL INCOME



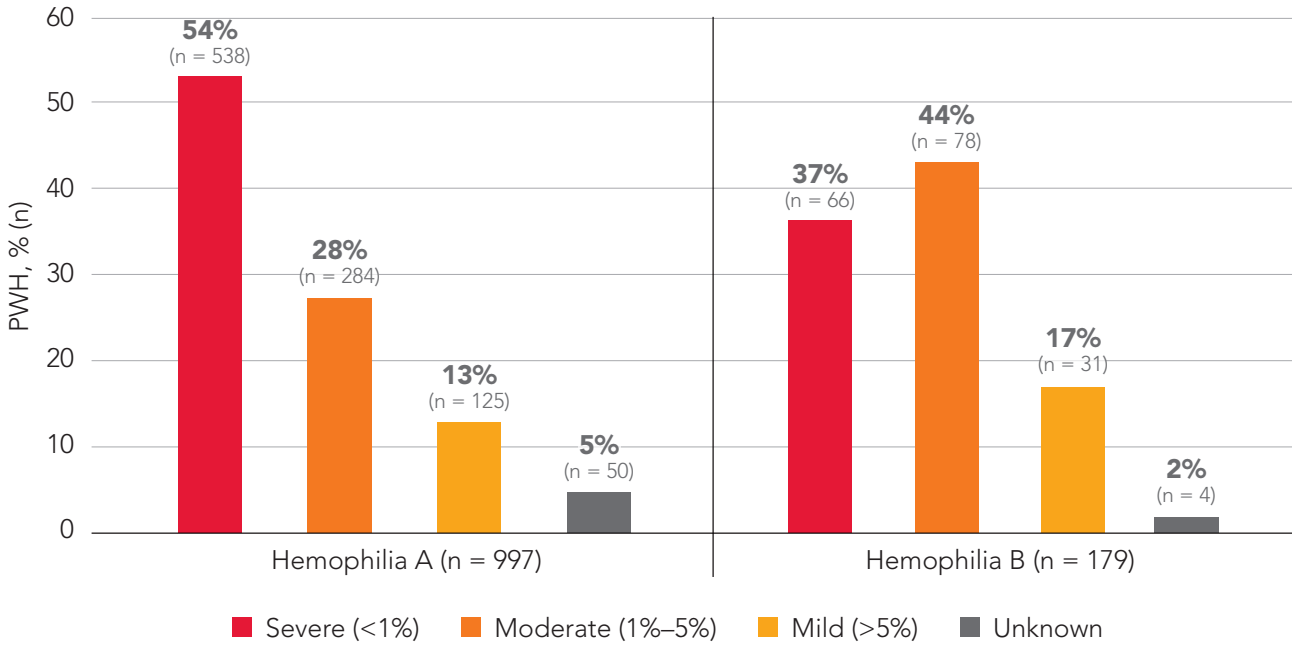
DEMOGRAPHICS

HEMOPHILIA TYPE AND SEVERITY

Overall, 98% of participants were male, 84% (n = 997) had hemophilia A, and 51% (n = 605) had severe disease (Table 2). The most frequent severity category among hemophilia A patients was severe (54%), while moderate category was the most common among hemophilia B patients (44%) (Figure 5). The unexpected higher proportion of moderate to severe hemophilia B patients may be due to the small number of enrolled hemophilia B patients at this early point in the WBDR.

FIGURE 5

HEMOPHILIA TYPE* AND SEVERITY, % (n)



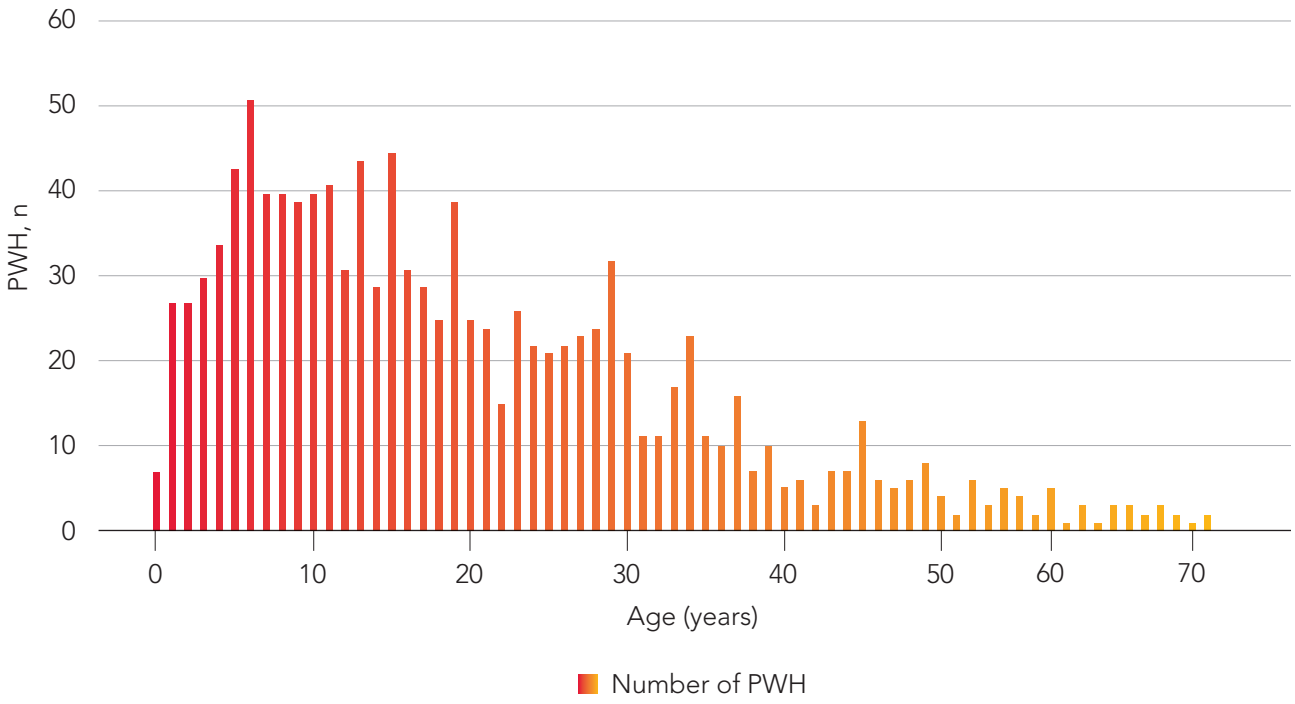
* Five PWH, including one severe, had unknown hemophilia type and were excluded from this graph

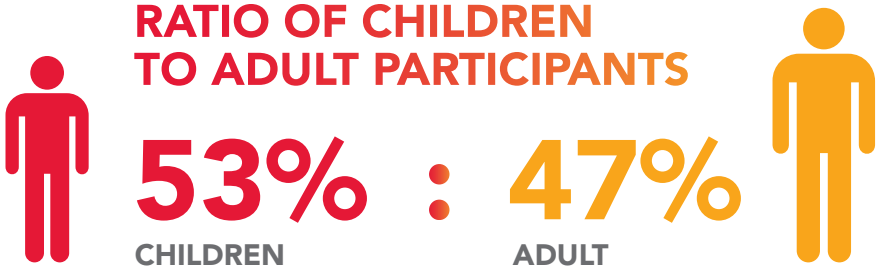
AGE OF PWH IN THE WBDR

The median age of participants was 16 years, ranging from 4 months to 76 years (Table 2, Figure 6). In 2018, children (<18 years of age) comprised 53% (n = 628) of all participants. The ratio of children to adult participants was 53% : 47% (Table 2).

FIGURE 6

AGE DISTRIBUTION OF PWH IN THE WBDR





AGE AT DIAGNOSIS

The median age (IQR) at diagnosis was 17 months (6–75) for all PWH, and 11 months (5–34) for severe PWH (Table 3). For all PWH, median age at diagnosis ranged from 45 months in South-East Asia to 9 months in the Americas (Figure 7), with a similar regional distribution among severe PWH. Age at diagnosis decreased as GNI increased, from 42 months in low income countries, to 9 months in high income countries for all PWH, with a similar pattern among PWH with severe disease (Figure 8).

There were 65 PWH newly diagnosed in 2018, with a median age of diagnosis of 54 months, ranging from 0 to 620 months (>51 years).

Forty per cent of all PWH and 44% of severe PWH were diagnosed before 12 months of age. Seventy per cent of all PWH and 78% of severe PWH were diagnosed before age 5 (Table 3, Figure 9).

17 **MONTHS**
MEDIAN AGE AT DIAGNOSIS

65 **NEWLY DIAGNOSED PATIENTS IN 2018**

FIGURE 7
AGE AT DIAGNOSIS BY REGION, months, median (IQR)

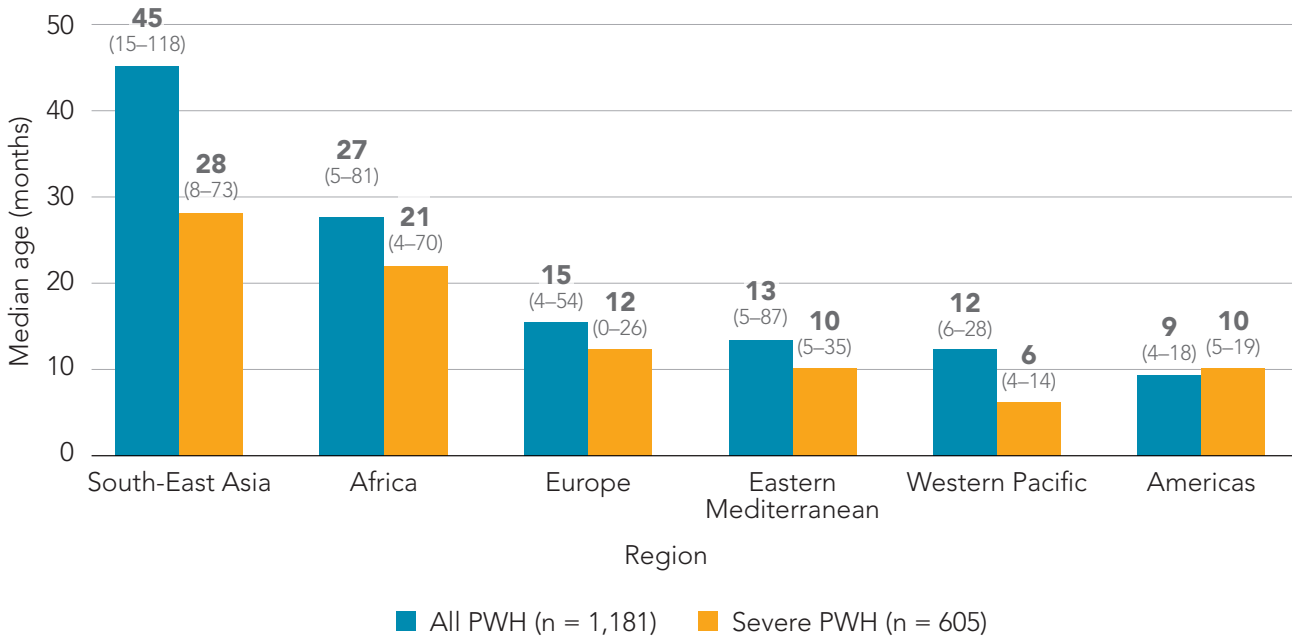
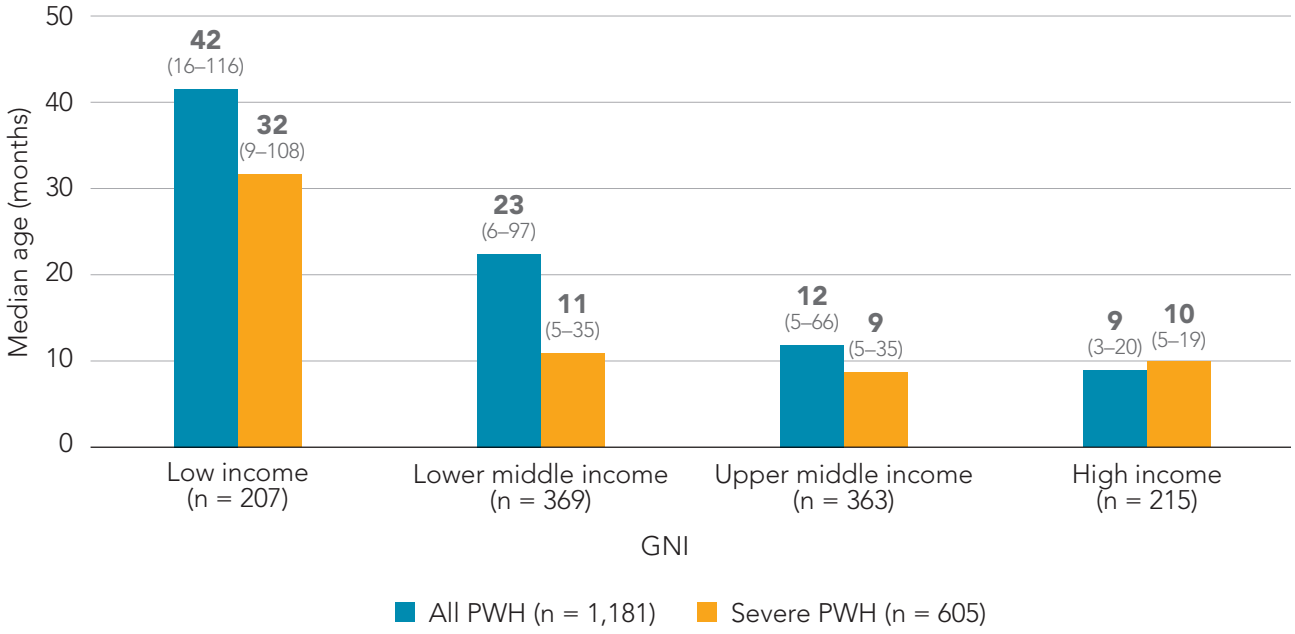


FIGURE 8

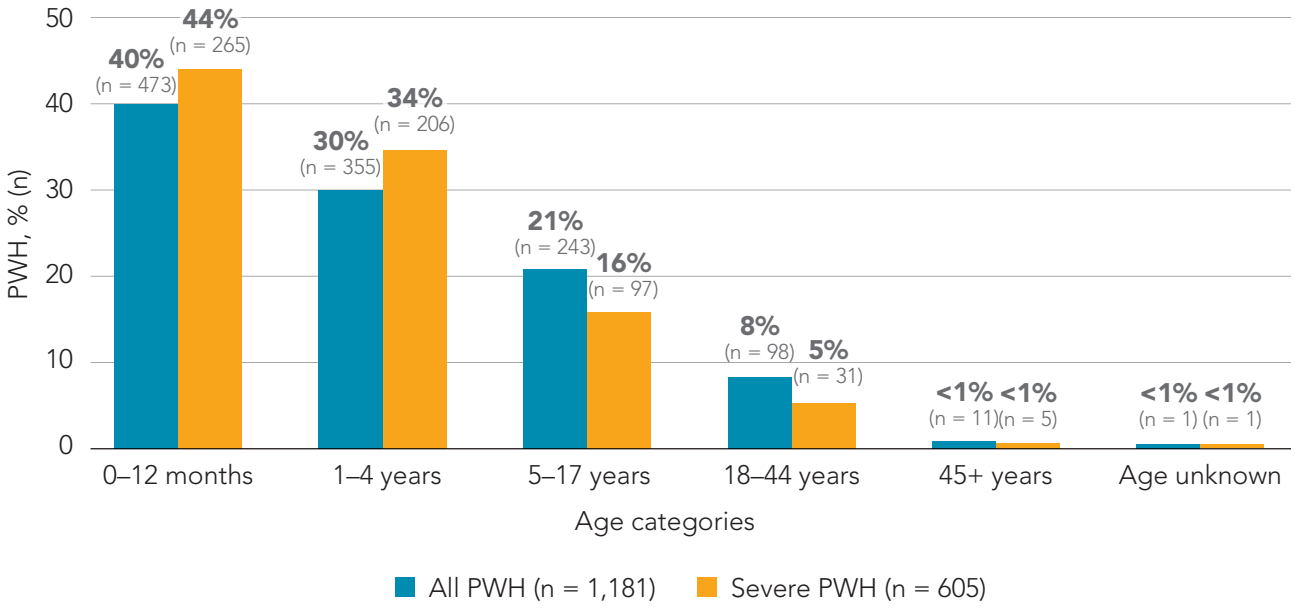
AGE AT DIAGNOSIS BY GROSS NATIONAL INCOME*, months, median (IQR)



* Gross National Income categories based on the World Bank Group 2017 rankings

FIGURE 9

AGE DISTRIBUTION OF PWH AT DIAGNOSIS, % (n)



AGE AT FIRST BLEED AND FIRST JOINT BLEED

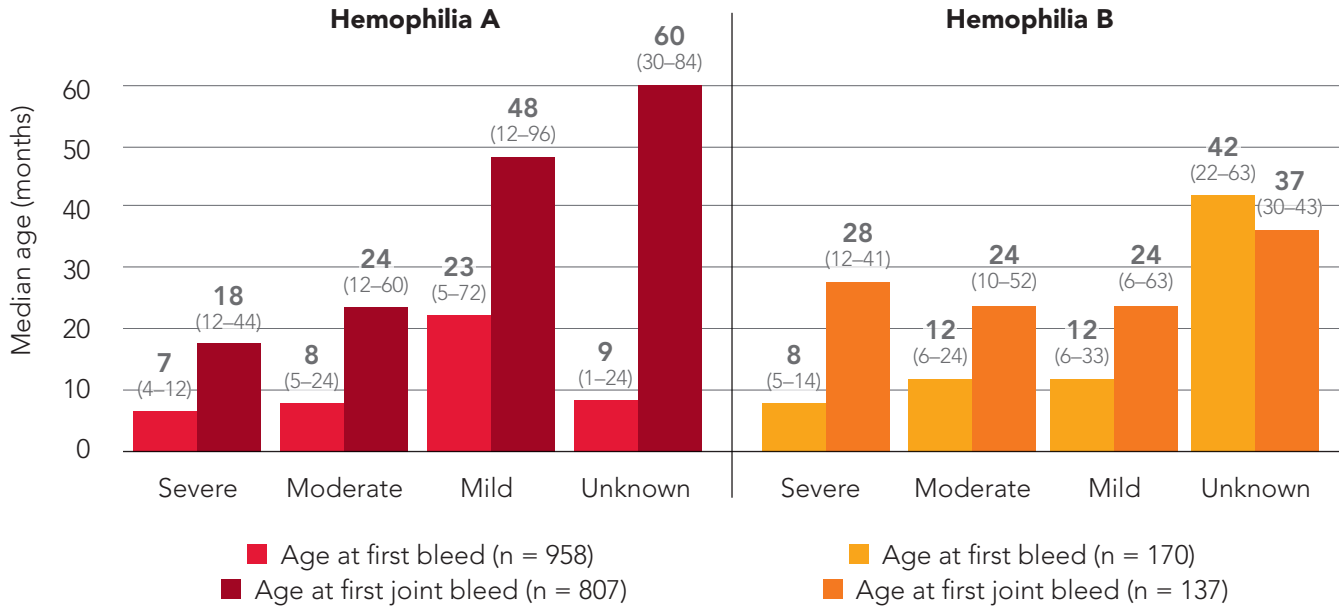
The median age at first bleed and first joint bleed were 8 and 24 months, respectively, for all PWH (Table 3). In general, both types of bleeds occured earlier in more severe hemophilia (Figure 10).

For people with hemophilia A, the median age at first bleed was 7 months for severe hemophilia, increasing to 23 months for mild hemophilia. The median age at first joint bleed was 18 months for severe hemophilia, increasing to 24 and 48 months for moderate and mild hemophilia, respectively (Figure 10; see Appendix 3, Table 7).

For people with hemophilia B, the median age at first bleed was 8 months for severe hemophilia and 12 months for both moderate and mild hemophilia. Median age at first joint bleed was 28, 24, and 24 months for severe, moderate, and mild PWH, respectively (Figure 10; see Appendix 3, Table 8).

FIGURE 10

AGE IN MONTHS AT FIRST BLEED AND FIRST JOINT BLEED BY SEVERITY, HEMOPHILIA A & B, months, median (IQR)



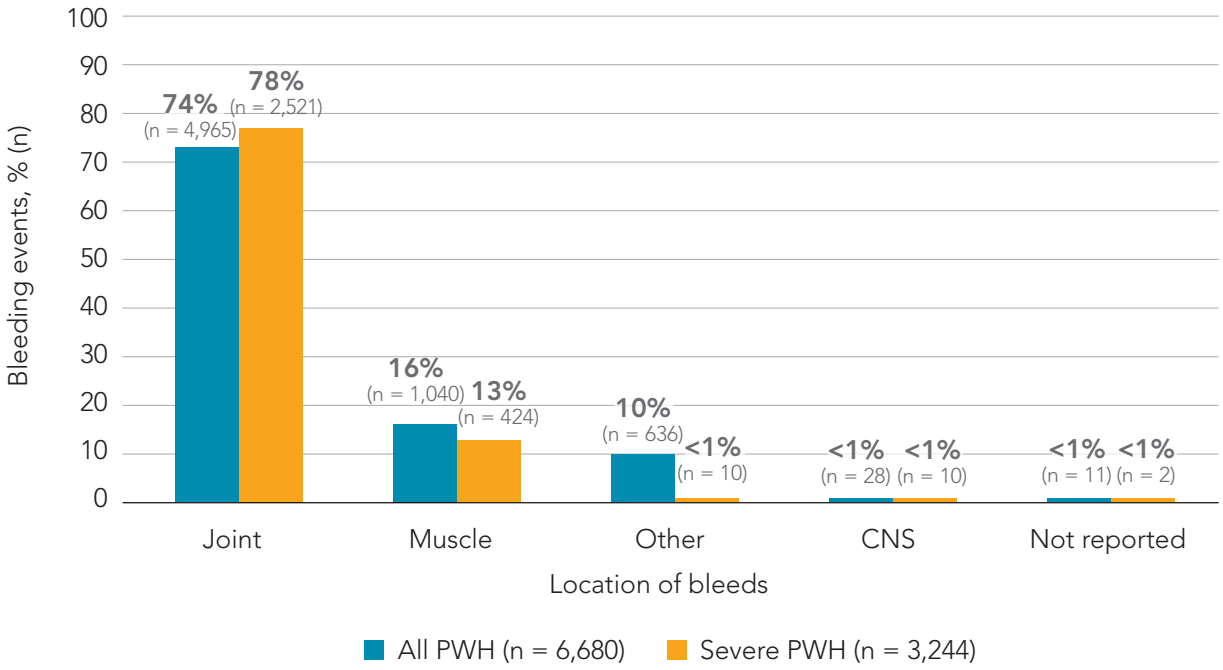
CLINICAL DATA

BLEEDING EVENTS

A total of 6,680 bleeds were reported by PWH. Of these, 4,965 (74.3%) were joint bleeds, 1,040 (15.6%) were muscle bleeds and 28 (<1%) were central nervous system (CNS) bleeds. There were 636 (9.5%) bleeds reported at 'other' locations, and the location of 11 (<1%) of bleeds was not reported (Figure 11). A total of 3,244 bleeds were reported by people with severe hemophilia. The distribution by location was similar to that of all PWH (Figure 11).

FIGURE 11

LOCATION OF BLEEDING EVENTS, % (n)



ANNUALIZED BLEEDING RATE AND ANNUALIZED JOINT BLEEDING RATE

The number of bleeds and joint bleeds reported at the baseline visit were recalculated as an annual rate to produce the annualized bleeding rate (ABR) and annualized joint bleeding rate (AJBR), respectively.

ANNUAL BLEEDING RATE

The median ABR (IQR) was 6 (2–16) for all PWH, and 6 (2–14) for severe PWH, varying by region and GNI (Figure 12; see Appendix 3, Table 9 for supplemental data table). The highest ABR, 20 (8–30), was observed in South-East Asia and the lowest ABR, 2 (0–10), was observed in Europe. An inverse relationship between ABR and GNI is demonstrated in Figure 12, with higher ABRs in regions with a higher proportion of PWH from low income countries, and lower ABRs in regions with a higher proportion of PWH from high income countries.

A closer look at annual bleeds by hemophilia type revealed a median ABR (IQR) of 6 (2–16) for hemophilia A and 4 (2–13) for hemophilia B (see Appendix 3, Table 10 for supplemental data table). Median annualized rates were also similar for severe hemophilia A (6 [2–14]) and hemophilia B (4 [2–10]).

ANNUAL JOINT BLEEDING RATE

Of the 792 PWH who reported at least 1 joint bleed, the median (IQR) AJBR was 8 (4–18) for all PWH, and 8 (4–16) for severe PWH, varying by region (Figure 13; see Appendix 3, Table 11 for supplemental data table). The highest AJBR, 16 (8–24), was observed in South-East Asia and the lowest AJBR, 4 (2–10), was observed in the Eastern Mediterranean region. Similar to ABR, an inverse relationship between ABR and GNI was observed.

Similar median annualized joint bleed rates (IQR) were observed for hemophilia A (8 [4–18]) and hemophilia B (8 [2–16]), and for severe hemophilia A (8 [4–16]) and severe hemophilia B (4 [2–12]); (see Appendix 3, Table 12 for supplemental data tables).

FIGURE 12

ABR BY REGION AND GNI, median (IQR)

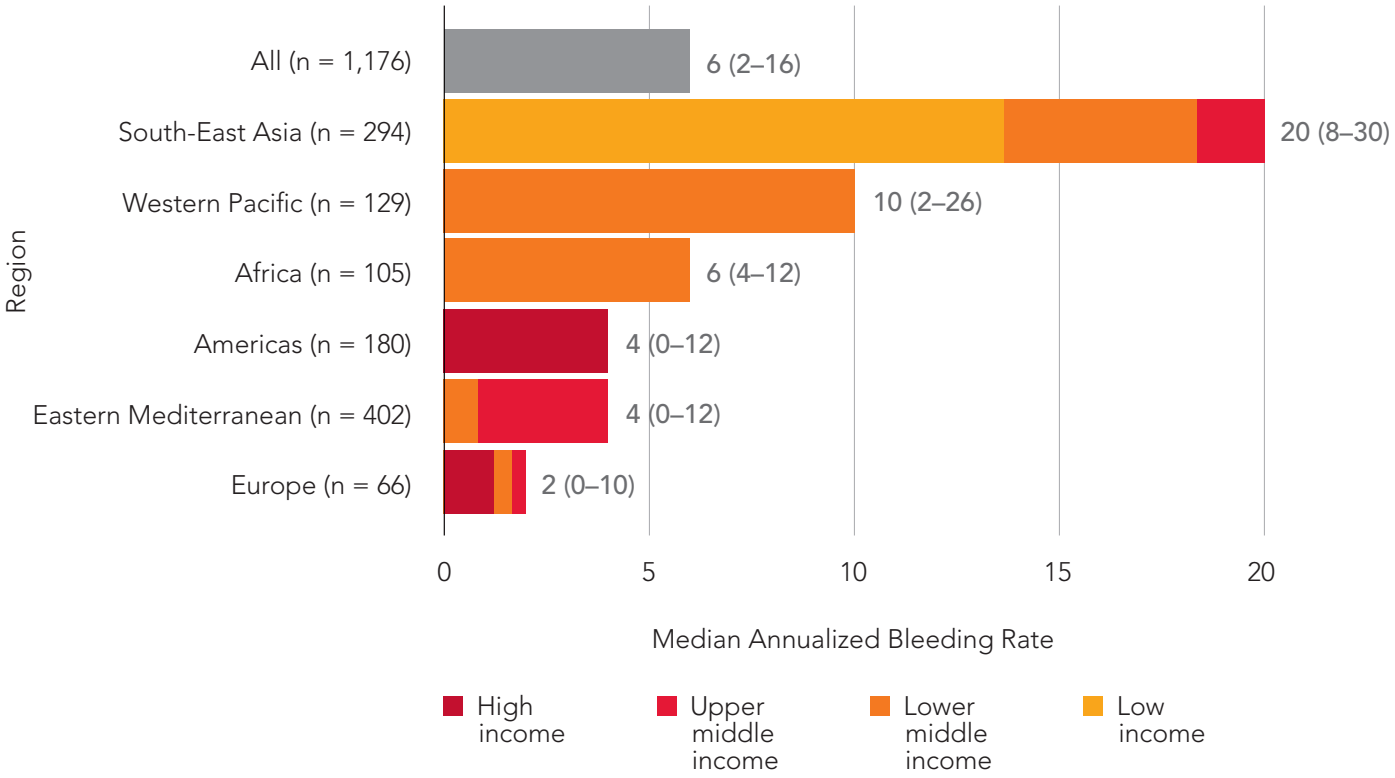
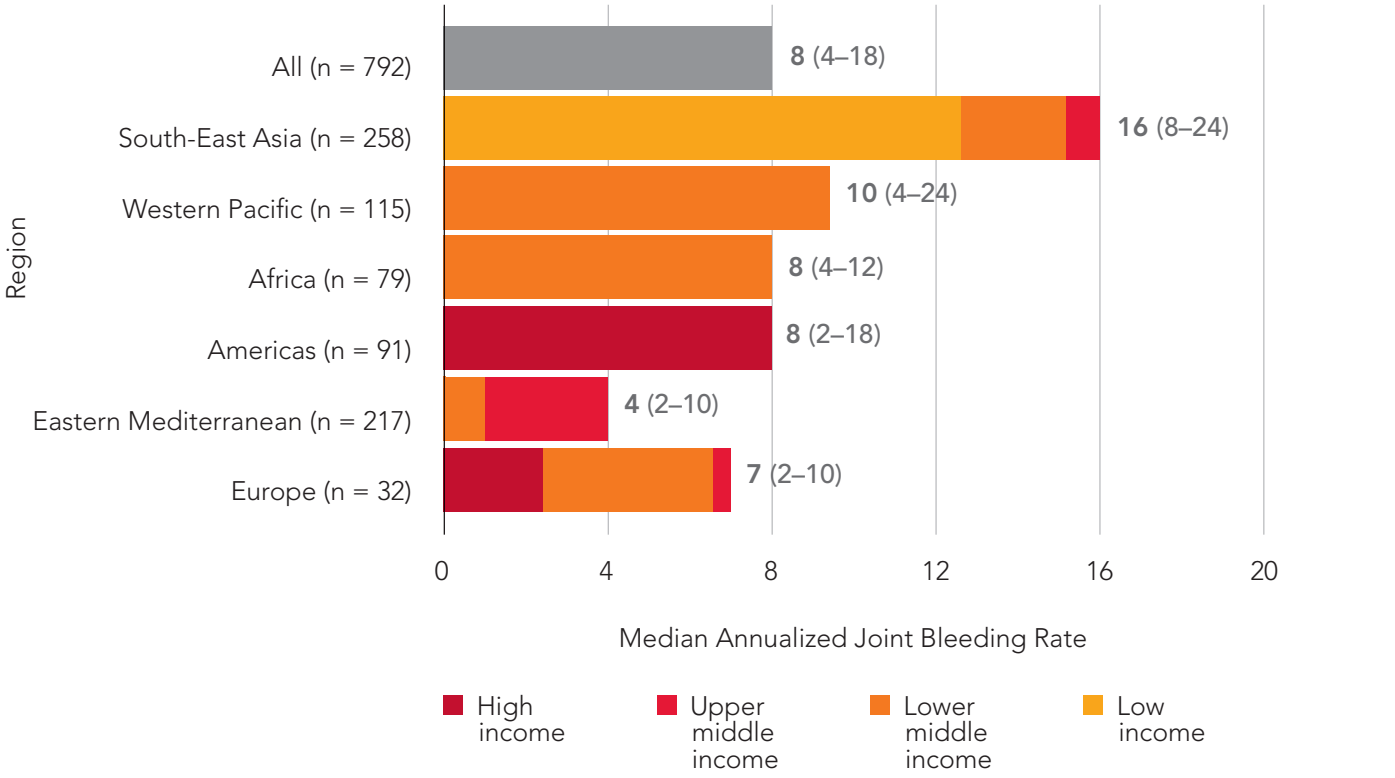


FIGURE 13

AJBR BY REGION AND GNI, median (IQR)

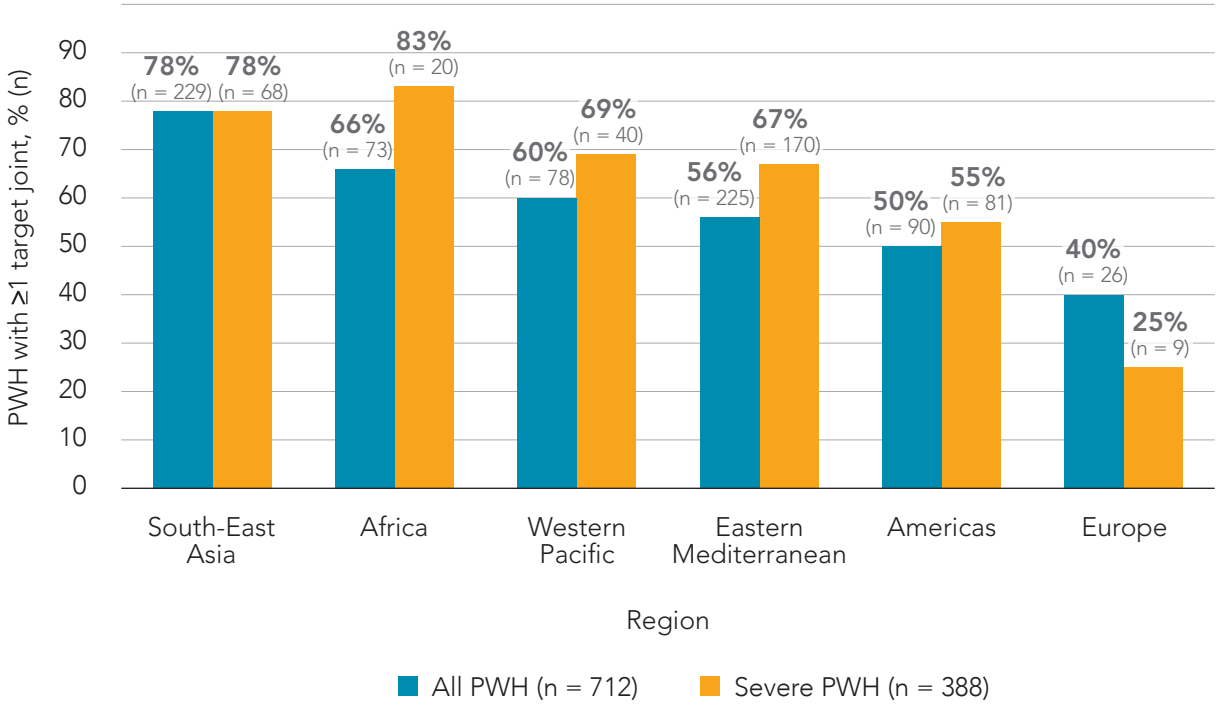


TARGET JOINTS

Sixty-one per cent of all PWH, and 64% of severe PWH, reported having at least one target joint in 2018. The proportion of PWH within each region reporting a target joint varied from 78% of all PWH in South-East Asia to 40% of all PWH in Europe; and from 83% of severe PWH in Africa to 25% of severe PWH in Europe (Figure 14).

FIGURE 14

PWH WITH AT LEAST 1 TARGET JOINT BY REGION



INHIBITORS

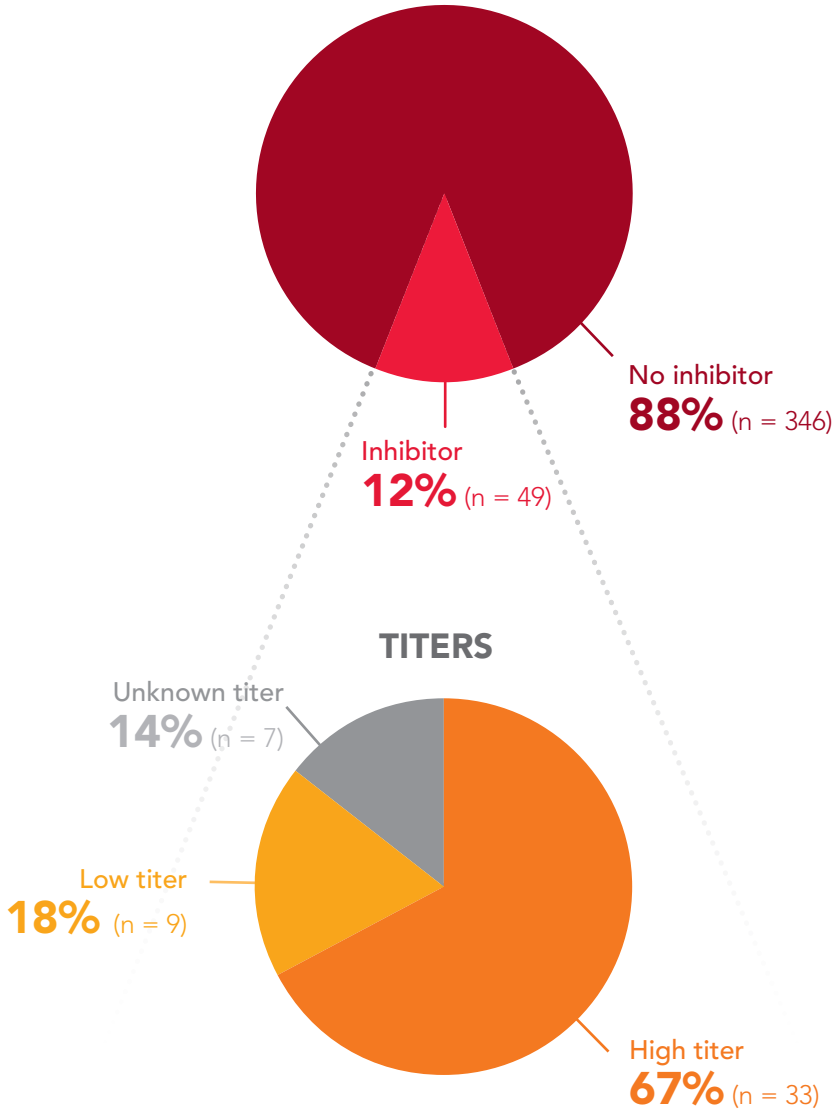
Data on inhibitor testing were based on baseline visit data. The number of PWH tested for inhibitors using the Bethesda assay, the Nijmegen-Bethesda- modification assay, or a mixing study (activated partial thromboplastin time) are reported. Results for the Bethesda assay, with and without Nijmegen modification, are expressed as titers, in Bethesda units (BU). Titers are not measured with the mixing study. The cut-off value for the presence of inhibitors is defined as ≥0.6 BU.[1] Low-titer inhibitors are defined as <5 BU and high-titer inhibitors are defined as ≥5 BU.[1]

In this report, the number of PWH with a positive inhibitor test is defined as any PWH who has had at least one positive inhibitor test in 2018.

395 PWH were tested for inhibitors, 49 (12.4%) were diagnosed with an inhibitor, and 346 (87.6%) were not diagnosed with an inhibitor. Of the PWH with an inhibitor, 9 (18.4%) had a low-titer inhibitor and 33 (67.3%) had a high-titer inhibitor. Titers could not be measured in 7 (14.3%) PWH who were tested using a mixing study (activated partial thromboplastin time) or unknown testing method (Figure 15).

FIGURE 15

PWH WITH INHIBITOR TEST (n = 395)

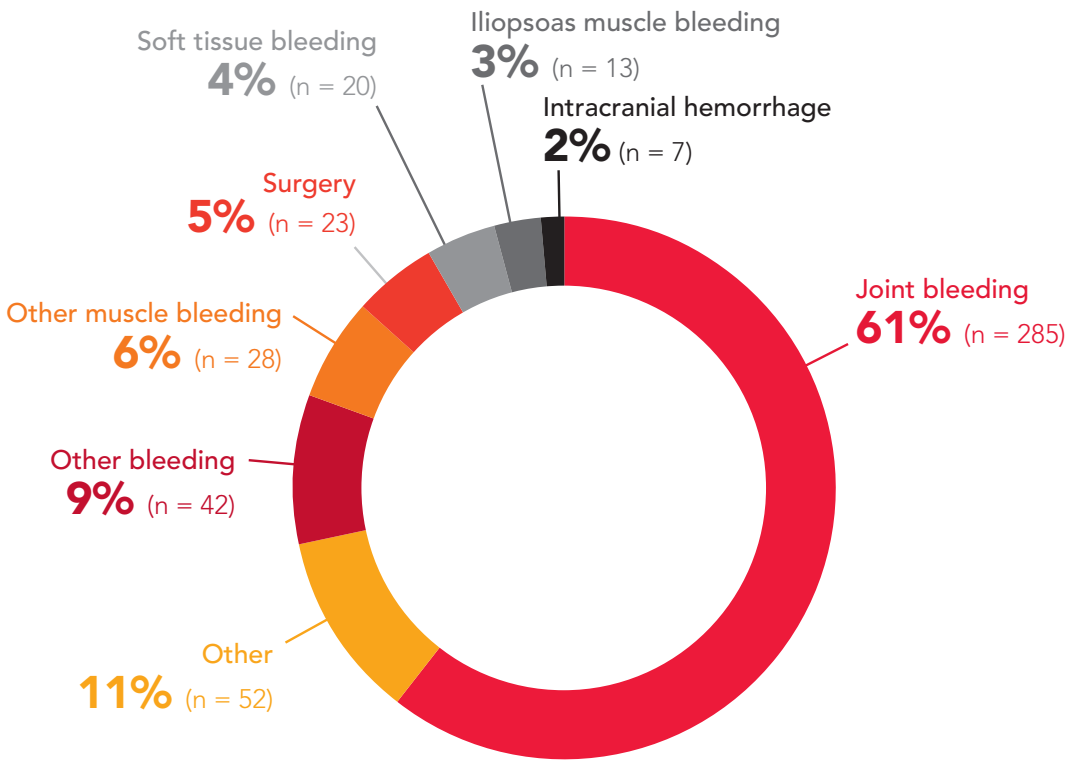


HOSPITALIZATION

In 2018, 249 PWH experienced a total of 587 hospitalizations, with a median stay (IQR) of 4 (3–6) days. The most common reason for hospitalization was joint bleed for both hemophilia A and B patients (61% and 58%, respectively; Figures 16 and 17). In total, eight PWH were hospitalized for an intracranial hemorrhage (7 [1.5%] of hospitalizations among hemophilia A patients and 1 [1%] among hemophilia B patients). One hemophilia B patient (and one hemophilia type unknown patient) were hospitalized for a thromboembolic event. The reasons for hospitalization were similar among persons with hemophilia A and B (four hospitalized PWH type unknown were excluded from Figures 16 and 17).

FIGURE 16

REASON FOR HOSPITALIZATION IN HEMOPHILIA A PATIENTS (n = 470)

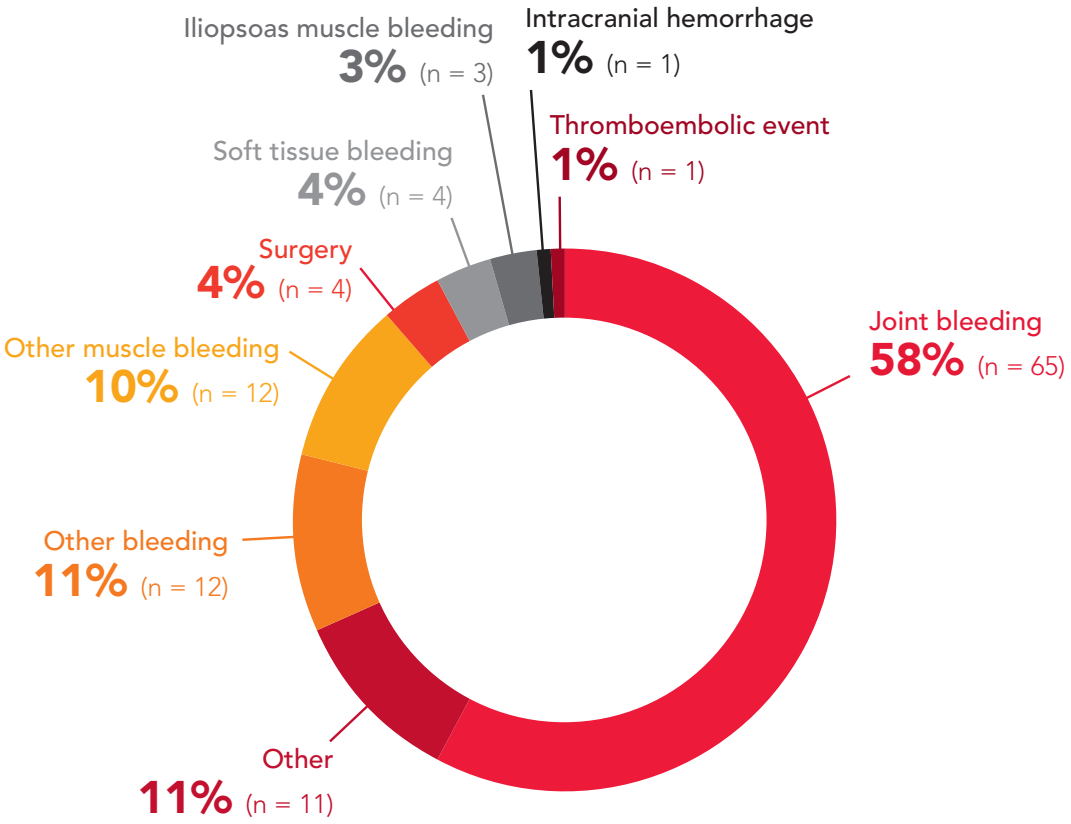


As a patient organization, our mission is to support, educate, and advocate for persons with bleeding disorders. All of these cannot be properly planned or executed without data. Now with our participation in the WBDR, data are available for effective advocacy, education, and support for our community.

— Megan Adediran, President/Executive Director
Haemophilia Foundation of Nigeria (five HTCs in Nigeria are participating in the WBDR)

FIGURE 17

REASON FOR HOSPITALIZATION IN HEMOPHILIA B PATIENTS (n = 113)

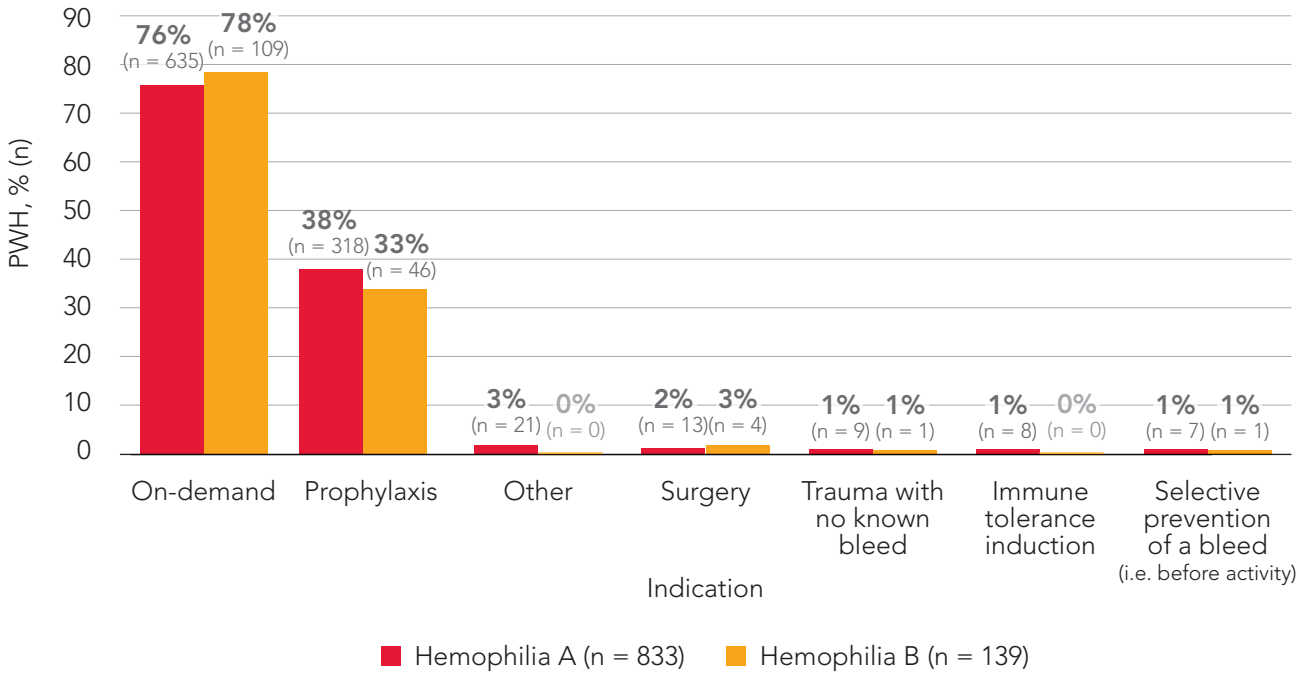


TREATMENT BY INDICATION

A total of 975 (83%) PWH received treatment in 2018. The most frequent indication reported for both hemophilia A and B patients was on-demand; 76% of hemophilia A patients and 78% of hemophilia B patients who received treatment in 2018, reported using on-demand treatment at least once in 2018. Prophylaxis was used by 38% of hemophilia A patients and 33% of hemophilia B patients, at some point in 2018. Regardless of hemophilia type, few PWH used treatment for surgery, immune tolerance induction, trauma with no known bleed, or selective prevention of a bleed (Figure 18).

FIGURE 18

TREATMENT INDICATION BY HEMOPHILIA TYPE, % (n)



* Three PWH had unknown hemophilia type and were excluded from this graph

PATIENTS USING

ON-DEMAND THERAPY IN 2018

76% HEMOPHILIA A

78% HEMOPHILIA B

PATIENTS USING

PROPHYLAXIS THERAPY IN 2018

38% HEMOPHILIA A

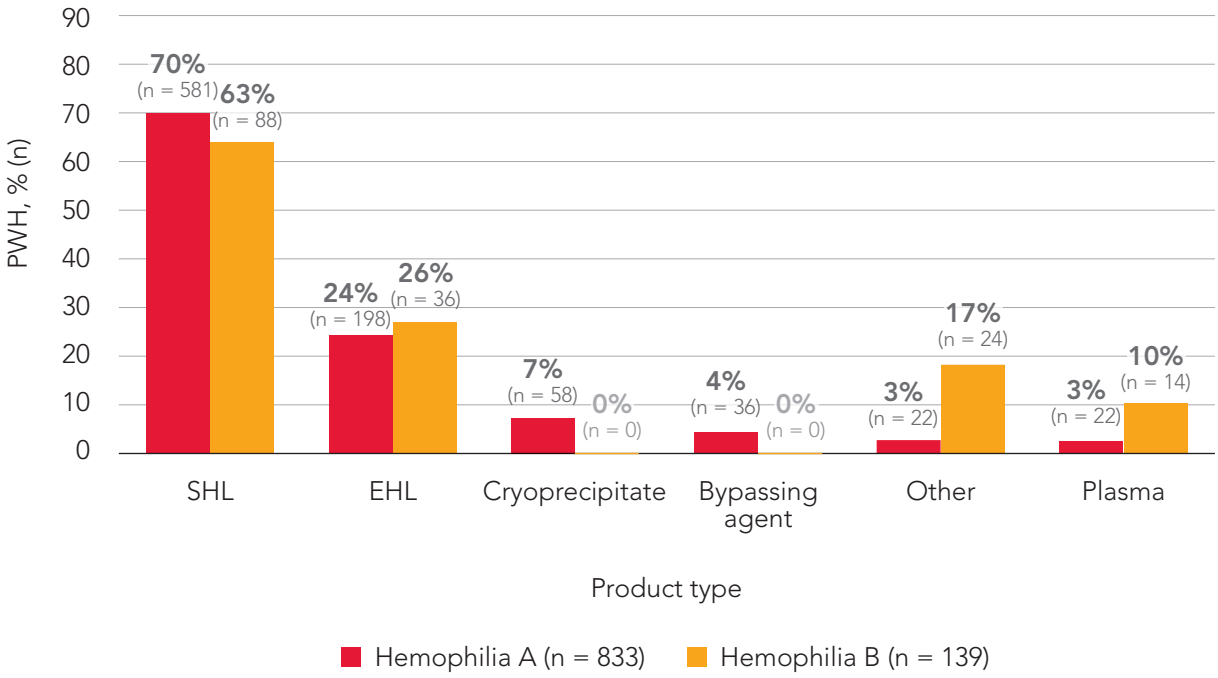
33% HEMOPHILIA B

TREATMENT BY CATEGORY

Standard half-life (SHL) clotting factor concentrates were the most common type of treatment (70% of hemophilia A patients and 63% of hemophilia B patients) followed by extended half-life (EHL) clotting factor concentrates (24% of hemophilia A patients and 26% of hemophilia B patients). A total of 58 (7%) persons with hemophilia A used cryoprecipitate (Figure 19).

FIGURE 19

PRODUCT CATEGORY BY HEMOPHILIA TYPE, % (n)



MORTALITY

There were three deaths in 2018 (0.25% mortality rate). All deaths occurred in PWH with severe hemophilia A, and were attributed to bleeding due to hemophilia (two cases of intracranial hemorrhage, one other bleeding event).

WBDR DATA QUALITY ACCREDITATION (DQA) PROGRAM

The objective of WBDR Data Quality Accreditation (DQA) Program is to standardize data collection procedures among HTCs, and to ensure that data entered in the WBDR are of high quality. A robust data cleaning and validation process is used to enhance data completeness, accuracy, and consistency. All data are evaluated on two data quality dimensions:

- Completeness: all data fields should be complete
- Accuracy: all data should be valid and consistent

The WFH data quality team works with all HTCs, providing training and feedback on the quality of all data. Incomplete and inconsistent data are communicated to HTCs via Data Clarification Forms, with requests to update data. Each HTC is evaluated on the overall level of data quality at their site, and classified according to the WBDR Data Quality Rating classification levels (Figure 20).

OVERALL, IN 2018, NEARLY

24 (83%) OF THE 29 HTCs

ACHIEVED THE HIGHEST LEVEL OF DATA QUALITY RATING, AND WERE **CLASSIFIED AS 'LEADERS'.**
(DATA QUALITY SCORE ≥95%)

For 2018 data, after receiving data quality feedback and training, 24 (83%) of the 29 HTCs achieved the highest level of data quality rating, and were classified as 'Leaders' (data quality score ≥95%). Three HTCs (10%) achieved the level of 'Advanced' (data quality score 85%–94%).

The data quality rating not only promotes a sense of ownership of quality data but also maintains the overall quality of the WBDR in the long run.

FIGURE 20

WBDR DATA QUALITY RATING

LEADERS
scored **95%–100%**
83% (24 HTCs)

ADVANCED
scored **85%–94%**
10% (3 HTCs)

INTERMEDIATE
scored **75%–84%**
3% (1 HTC)

DEVELOPED
scored **50%–74%**
3% (1 HTC)

BASIC
scored **0%–49%**
0% (0 HTCs)

The data quality of my HTC database has been significantly improved and medical staff can manage patients and their hospital admissions more easily. We can easily see our patients' medical history and their joint bleeds so we're able to have a suitable treatment for them. In the future, we hope to use this database for advocacy.

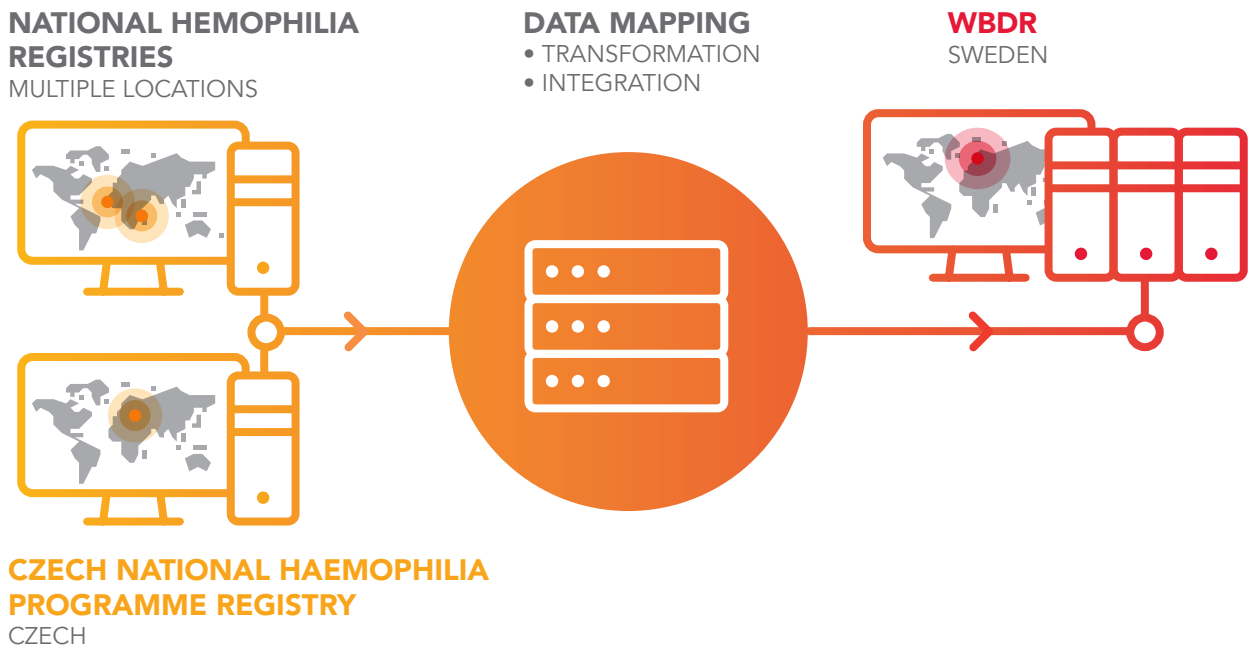
— Nguyen Thanh Phong, MD
Blood Transfusion Hematology Hospital, Ho Chi Minh City, Vietnam

LINKING PATIENT REGISTRY DATA

Registries, with international collaboration between countries, are the best way to pool sufficient data to increase knowledge and evidence in rare disorders. In an effort to combine resources from existing hemophilia registries, and maximize the utility of data that currently exist, the development of the WBDR includes an international data integration component with the aim of facilitating data transfer from existing patient registries to the WBDR.

As part of a proof-of-concept study, an export of de-identified data from the 2017 Czech National Haemophilia Programme Registry (CNHPR) will be imported into the WBDR. This import will be based on a minimal set of data common to both registries. Data on 775 patients will be imported from the CNHPR to the WBDR. The CNHPR is a national registry, which collects data from eight pediatric and eight adult hemophilia centres. The data reported in the CNHPR represent 100% of identified patients in the Czech Republic.

A protocol to import data from existing patient registries into the WBDR is currently in development, based on the proof-of-concept study. The program is available to interested countries who want to set up an import process to combine their national data with the WBDR. Interested individuals are encouraged to contact the WFH at wbdr@wfh.org.



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 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.

— Jan Blatny, MD, PhD
Czech National Haemophilia Programme Registry (CNHPR)

WBDR RESEARCH SUPPORT PROGRAM

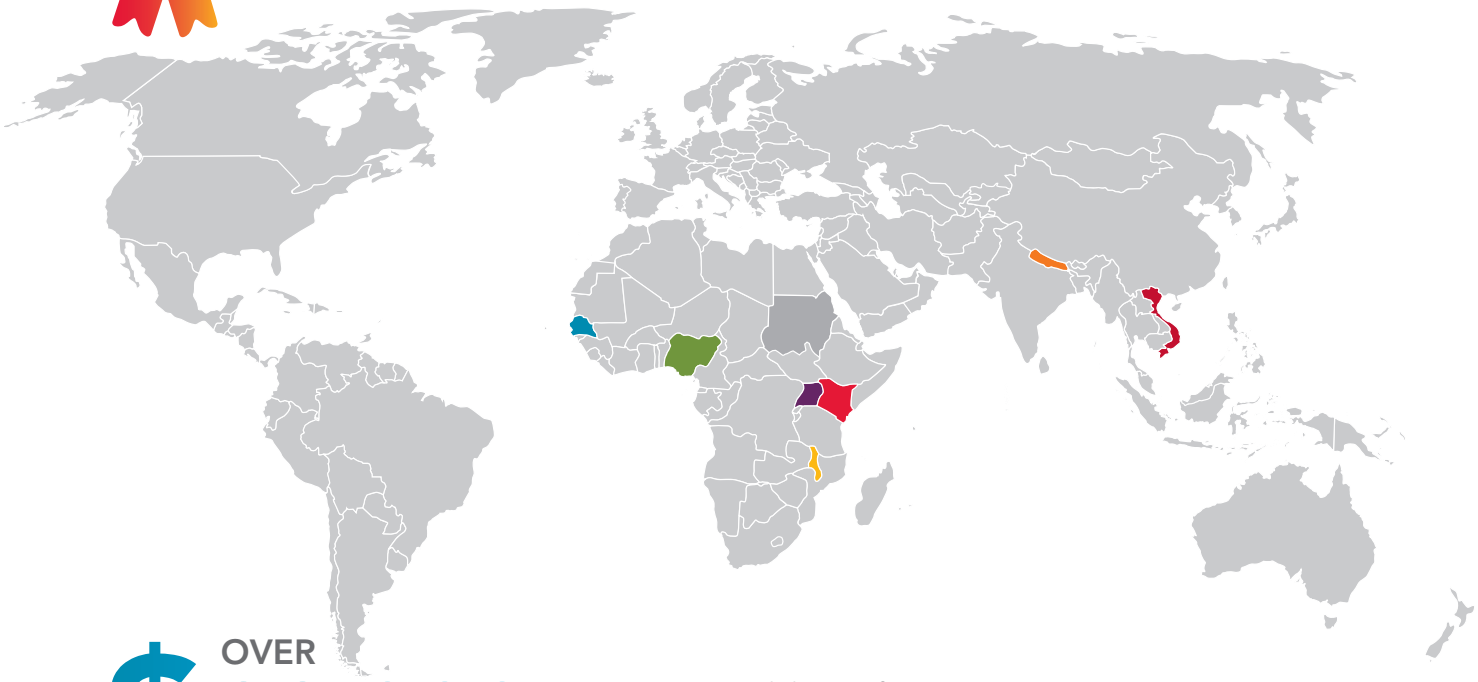
The WBDR is dedicated to improving the lives of PWH by collecting high-quality data that can be used for research and advocacy, by the WBDR community of investigators and PWH.

The WBDR Research Support Program is designed to provide small research funding to encourage the use of WBDR data. This program is open to all participating HTCs. In 2018, eight investigators were awarded funding for a period of one or two years.

Congratulations to the eight HTCs who were awarded funding for their research project!

WINNERS OF RESEARCH SUPPORT PROGRAM

8 AWARDS GRANTED



OVER $32,000

- Centre National de Transfusion Sanguine, Senegal
- Civil Service Hospital, Kathmandu, Nepal
- Hemophilia Treatment Center, University of Khartoum, Sudan
- Kamuzu Central Hospital, Lilongwe, Malawi
- Kenyatta National Hospital, Nairobi, Kenya
- Lagos University Teaching Hospital, Lagos, Nigeria
- Mulago Hospital, Kampala, Uganda
- National Institute of Hematology and Blood Transfusion, Hanoi, Vietnam

The 2019 WBDR Research Support Program application cycle opens on June 1, 2019. For more information, please visit: https://www.wfh.org/en/our-work/wbdr-research-support-program.

APPENDIX 1 – GLOBAL REPRESENTATION IN THE WBDR, 2019

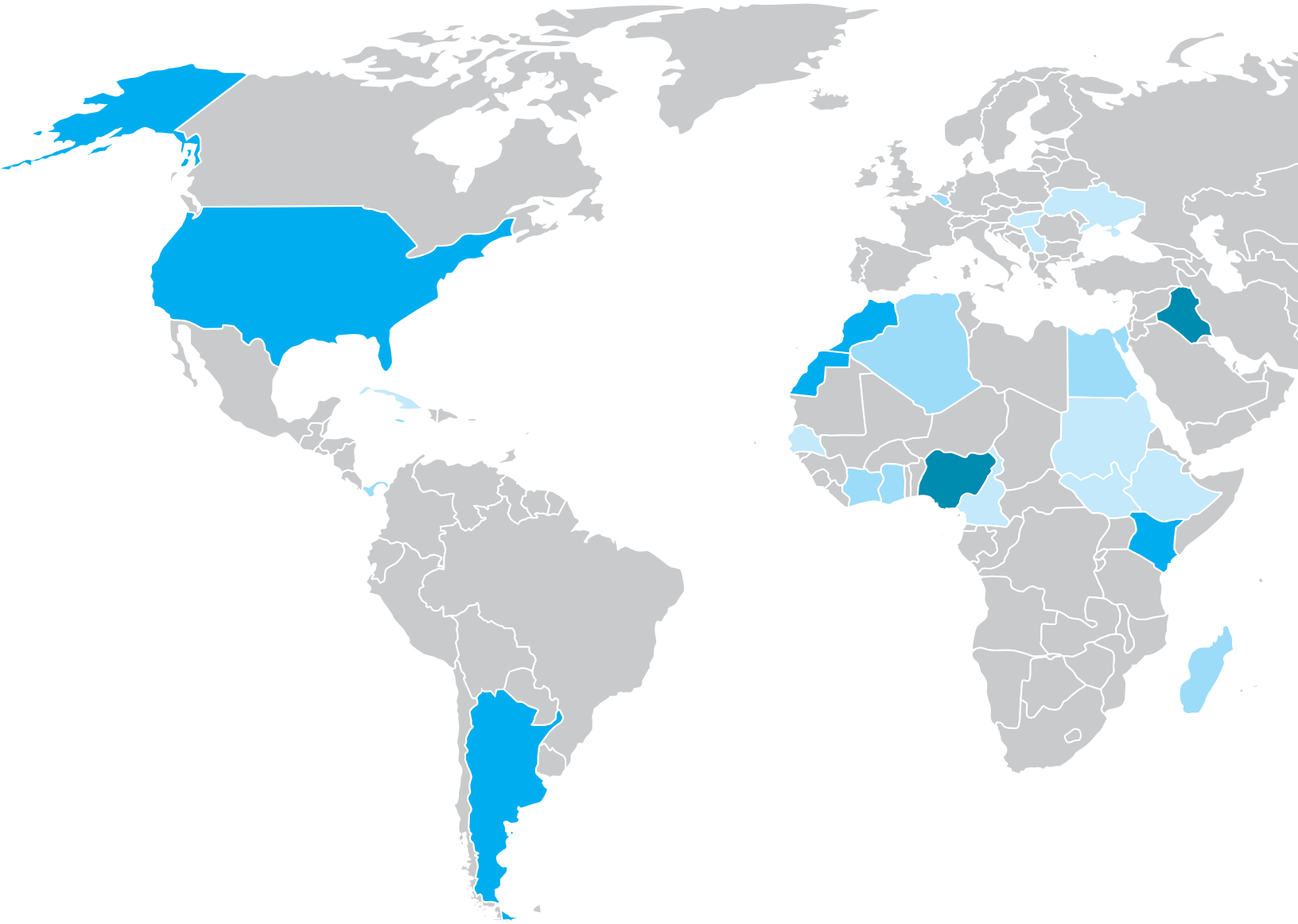
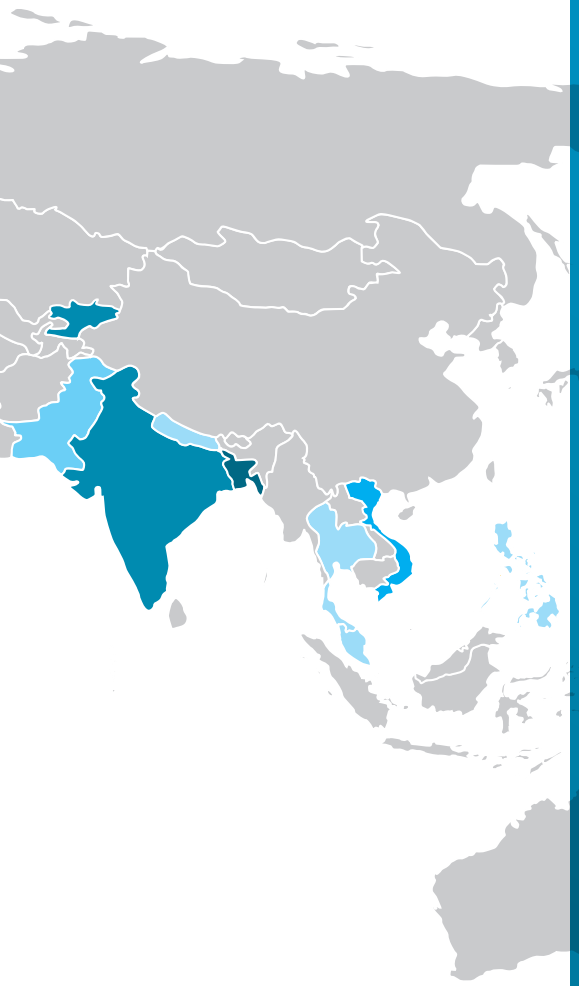


FIGURE 21

GLOBAL REPRESENTATION IN THE WBDR AS OF APRIL 2019

1 → 6 Number of HTCs per countries



AMERICAS

ARGENTINA
Fundación de la Hemofilia, Buenos Aires

CARDHE, Bahía Blanca

CUBA
Instituto de Hematología e Inmunología, Havana

JAMAICA
University Hospital of the West Indies, Kingston

PANAMA
Hospital del Niño, Panamá City

USA
University of Cincinnati Hemophilia Treatment Center, Cincinnati

Wake Forest Baptist Health, Winston Salem

EUROPE

BELGIUM
Cliniques Universitaires Saint Luc, Woluwe Saint Lambert

HUNGARY
National Haemophilia Centre, Budapest

KYRGYZSTAN
National Center of Oncology and Hematology, Bishkek

National Center for Maternity and Childhood, Bishkek

Adult Hematology – Osh Interregional Joint Clinical Hospital, Osh

SERBIA
Mother and Child Health Care Institute of Serbia "Dr Vukan Cupic", Belgrade

UKRAINE
SI "Institute of blood pathology and transfusion medicine of UNAMS", Lviv

SOUTH-EAST ASIA

BANGLADESH
Dhaka Medical College Hospital, Dhaka

Chittagong Medical College Hospital, Chittagong

Bangabandhu Sheikh Mujib Medical University, Dhaka

Lab One Foundation, Dhaka

Dhaka Shishu Hospital, Dhaka

Rajshahi Medical College Hospital, Rajshahi

INDIA
Haemophilia Treatment Centre, District Hospital, Aluva

Christian Medical College, Ludhiana

Melaka Manipal Medical College, Hemophilia Society Manipal, Udupi

NEPAL
Civil Service Hospital, Kathmandu

THAILAND
Chiang Mai University Hospital, Chiang Mai

AFRICA

CAMEROON
CHU Yaoundé, Yaoundé

ETHIOPIA
Tikur Anbessa Hospital, Addis Ababa

GHANA
Komfo Anokye Teaching Hospital, Kumasi

IVORY COAST
CHU de Yopougon, Abidjan

KENYA
Kenyatta National Hospital, Nairobi

Moi Teaching and Referral Hospital, Eldoret

MADAGASCAR
CHU Joseph Ravoahangy Andrianavalona (HJRA), Antananarivo

NIGERIA
National Hospital, Abuja

University of Nigeria Teaching Hospital, Enugu State

Lagos University Teaching Hospital, Lagos

Aminu Kano Teaching Hospital, Kano

SENEGAL
Centre National de Transfusion Sanguine, Dakar

EASTERN MEDITERRANEAN

ALGERIA
Unité hémophilie et maladies hémorragiques héréditaires, Constantine

EGYPT
Shabrawishi Hospital, Giza

IRAQ
Hemophilia Center Medical City, Baghdad

National Center of Hematology Al Mustansirya University, Baghdad

Basra Center for Hereditary Blood Diseases, Basra

MOROCCO
Enfants – Centre de Traitement de l'hémophilie de Rabat, Hôpital d'Enfants de Rabat

Acute Medical Unit, University Hospital Ibn Sina, Mohammed V University in Rabat

PAKISTAN
Haemophilia Treatment Centre, Rawalpindi

Haemophilia Treatment Centre, Lahore

SUDAN
Haemophilia Treatment Centre, Khartoum

WESTERN PACIFIC

MALAYSIA
Hospital Ampang, Kuala Lumpur

PHILIPPINES
University of Santo Tomas Hospital, Manila

VIETNAM
Blood Transfusion Hematology, Ho Chi Minh City

National Institute of Hematology and Blood Transfusion, Hanoi

APPENDIX 2 – DATA SETS

MINIMAL DATA SET, Extended Data Set

DEMOGRAPHICS	DIAGNOSTICS	CLINICAL
Date of birth	**Date of diagnosis**	**Bleeding events**
Gender	**Hemophilia type**	**Target joints**
Country of residence	**Hemophilia severity**	**Treatments**
Employment	**Hemophilia factor level**	**Inhibitor status**
Education	**Inhibitor history**	**Hospitalization**
Marital status	**Treatment history**	**Mortality**
	Bleeding history	Adverse events
	Genetic testing	Co-morbidities
	Blood type	Functional scales*
	Family history	Quality of life scales†

Fields identified in bold represent the minimal data set.
* Functional scales include: Haemophilia Joint Health Score, Joint Disease, Range of Motion, WFH Gilbert Score, Functional Independence Score for Haemophilia
† Quality of life scale: EQ-5D-5L

APPENDIX 3 – SUPPLEMENTAL TABLES

TABLE 7

MEDIAN AGE IN MONTHS AT FIRST BLEED AND FIRST JOINT BLEED BY SEVERITY, Hemophilia A

	HEMOPHILIA A (n = 997)	
SEVERITY	**Age at first bleed, months** median, IQR (n = 958)*	**Age at first joint bleed, months** median, IQR (n = 807)†
Severe (<1%)	**7 (4–12)** (n = 516)	**18 (12–44)** (n = 437)
Moderate (1%–5%)	**8 (5–24)** (n = 276)	**24 (12–60)** (n = 251)
Mild (>5%)	**23 (5–72)** (n = 116)	**48 (12–96)** (n = 79)
Unknown	**9 (1–24)** (n = 50)	**60 (30–84)** (n = 40)

* Not reported for 39 PWH
† Not reported for 190 PWH

TABLE 8

MEDIAN AGE IN MONTHS AT FIRST BLEED AND FIRST JOINT BLEED BY SEVERITY, Hemophilia B

	HEMOPHILIA B (n = 179)	
SEVERITY	**Age at first bleed, months** median, IQR (n = 170)*	**Age at first joint bleed, months** median, IQR (n = 137)†
Severe (<1%)	**8 (5–14)** (n = 64)	**28 (12–41)** (n = 58)
Moderate (1%–5%)	**12 (6–24)** (n = 75)	**24 (10–52)** (n = 61)
Mild (>5%)	**12 (6–33)** (n = 27)	**24 (6–63)** (n = 16)
Unknown	**42 (22–63)** (n = 4)	**37 (30–43)** (n = 2)

* Not reported for nine PWH
† Not reported for 42 PWH

TABLE 9

MEDIAN ANNUAL BLEEDING RATE BY REGION

REGION	ANNUAL BLEEDING RATE, Median (IQR)	
	ALL PWH (n = 1,176)*	SEVERE PWH (n = 604)†
Total	**6 (2–16)**	**6 (2–14)**
South-East Asia	**20 (8–30)** (n = 294)	**24 (8–36)** (n = 87)
Western Pacific	**10 (2–26)** (n = 129)	**16 (8–28)** (n = 58)
Africa	**6 (4–12)** (n = 105)	**8 (4–12)** (n = 23)
Americas	**4 (0–12)** (n = 180)	**4 (0–12)** (n = 147)
Eastern Mediterranean	**4 (0–12)** (n = 402)	**4 (0–8)** (n = 253)
Europe	**2 (0–10)** (n = 66)	**2 (0–5)** (n = 36)

* Not reported for five PWH
† Not reported for one PWH

TABLE 10

MEDIAN ANNUAL BLEEDING RATE BY HEMOPHILIA TYPE

HEMOPHILIA TYPE	ANNUAL BLEEDING RATE, Median (IQR)	
	ALL PWH (n = 1,176)*	SEVERE PWH (n = 604)*
Hemophilia A	**6 (2–16)** (n = 989)	**6 (2–14)** (n = 537)
Hemophilia B	**4 (2–13)** (n = 179)	**4 (NA)** (n = 66)
Unknown	**8 (4–24)** (n = 5)	**2 (NA)** (n = 1)

* Not reported for five PWH
NA = not applicable

TABLE 11

MEDIAN ANNUAL JOINT BLEEDING RATE BY REGION

REGION	ANNUAL JOINT BLEEDING RATE, Median (IQR)	
	ALL PWH (n = 792)*	SEVERE PWH (n = 404)
Total	**8 (4–18)**	**8 (4–16)**
South-East Asia	**16 (8–24)**	**20 (8–26)**
Western Pacific	**10 (4–24)**	**14 (6–26)**
Africa	**8 (4–12)**	**8 (4–12)**
Americas	**8 (2–18)**	**10 (4–22)**
Eastern Mediterranean	**4 (2–10)**	**4 (2–10)**
Europe	**7 (2–10)**	**4 (2–10)**

* Data are based on all PWH who reported at least 1 joint bleed

TABLE 12

MEDIAN ANNUAL JOINT BLEEDING RATE BY HEMOPHILIA TYPE

HEMOPHILIA TYPE	ANNUAL JOINT BLEEDING RATE, Median (IQR)	
	ALL PWH (n = 792)	SEVERE PWH (n = 404)
Hemophilia A	**8 (4–18)** (n = 670)	**8 (4–16)** (n = 357)
Hemophilia B	**8 (2–16)** (n = 116)	**4 (NA)** (n = 46)
Unknown	**6 (2–14)** (n = 5)	**2 (NA)** (n = 1)

NA = not applicable

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THANK YOU

THANK YOU TO PWH

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

THANK YOU 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!

THANK YOU TO SPONSORS

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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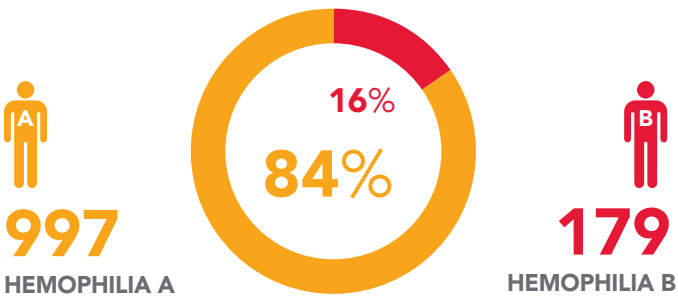
NOTE

WBDR 2018 HIGHLIGHTS

19
COUNTRIES REPRESENTED

29
HTCs PARTICIPATING

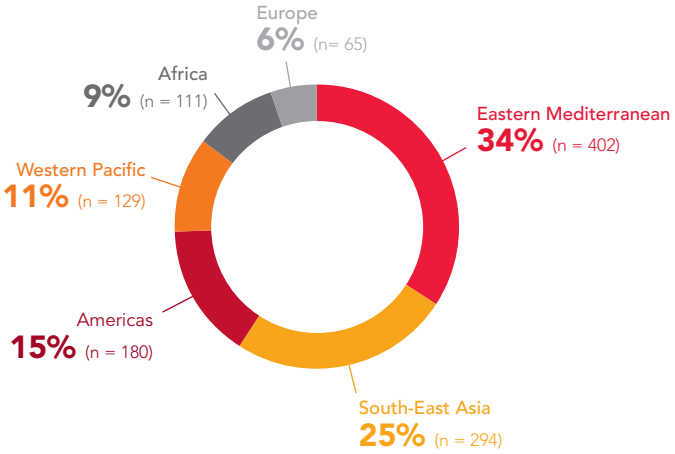
1,181
PEOPLE WITH HEMOPHILIA ENROLLED



997
HEMOPHILIA A

179
HEMOPHILIA B

DISTRIBUTION OF PWH BY REGION



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