

October 2015

World Federation of Hemophilia Report on the

ANNUAL GLOBAL SURVEY 2014



WFH

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

Report on the Annual Global Survey 2014 is published by the World Federation of Hemophilia.

All data are provisional.

© World Federation of Hemophilia, 2015

To obtain permission to reprint, redistribute, or translate this publication, please contact the Education and Public Policy Department at the address below.

When this data is used in publications or other research the World Federation of Hemophilia must be credited. We encourage researchers to contact us in the event they use the Global Survey data.

Please note: This material is intended for general information only. The World Federation of Hemophilia does not endorse particular treatment products or manufacturers; any reference to a product name is not an endorsement by the World Federation of Hemophilia. The World Federation of Hemophilia is not a regulatory agency and cannot make recommendations relating to safety of manufacturing of specific blood products. For recommendations of a particular product, the regulatory authority in a particular country must make these judgments based on domestic legislation, national health policies and clinical best-practices.

World Federation of Hemophilia

1425, boul. René-Lévesque Ouest, bureau 1010
Montréal, Québec H3G 1T7
Canada

Tel. (514) 875-7944

Fax: (514) 875-8916

E-mail: wfh@wfh.org

Website: www.wfh.org

Table of contents

Introduction.....	1
Summary of survey data.....	3
Graphs – number of identified patients.....	4
Graphs – factor usage.....	5
Data Source.....	13
Severity.....	14
Countries included in the survey.....	16
Population statistics.....	17
Distribution of reported bleeding disorders.....	20
Gender distribution.....	23
Patients with inhibitors.....	24
Age distribution hemophilia and VWD.....	26
HIV and HCV infection.....	32
Reported use of prophylaxis.....	34
Reported use of factor concentrates.....	35
Annual Global Survey 2014 questionnaire.....	39
Glossary.....	48



Introduction to the Report on the Annual Global Survey 2014

Report on the Annual Global Survey 2014 includes selected demographic and other data on people with hemophilia (PWH), von Willebrand disease (VWD), other rare factor deficiencies, and inherited platelet disorders throughout the world. The purpose of this report is to provide hemophilia organizations, hemophilia treatment centres (HTCs), and health officials with useful information to support efforts to improve or sustain the care of people with bleeding disorders and to assist with program planning. Supplementary charts and graphs using 2014 data can be found on the website at: www.wfh.org/en/data-collection.

Methodology

In 1998, the World Federation of Hemophilia (WFH) began collecting information on hemophilia care throughout the world. This survey, called the WFH Annual Global Survey, collects basic demographic information, data on access to care and treatment products, and information on the prevalence (the percentage of the population affected) of infectious complications such as HIV and hepatitis C (HCV). The WFH compiled the first survey report in 1999.

Each year questionnaires are sent to national hemophilia associations linked with the WFH with the request that they in turn work with physicians or health officials, as necessary, to complete the survey. The WFH reviews completed questionnaires for inconsistencies, which are clarified where possible by communicating directly with the participating organization. The 2014 survey is the fifteenth WFH survey. This report also uses data from the years 2012 and 2013. Not all of our members are able to report every year. Previous Annual Global Survey reports have used historical data going back more than 2 years. A list of participating countries and the last year they provided data can be found on page 16. This report includes data on more than 287,000 people with hemophilia, von Willebrand disease and other bleeding disorders in 106 countries. Data from the WFH questionnaire are supplemented with data from other sources in order to provide a general socio-economic picture of each country surveyed. The survey questionnaire is included at the end of this report.

Comments on the graphs

The graph showing the increase over time in patients identified contains historical data from the Annual Global Survey. This graph was created using aggregated numbers to demonstrate the increases in patients identified over time. If a country reported data one year and not the next, the older data were used on the assumption that the number of patients did not change substantially from one year to the next. For all the graphs, answers were not always available for all questions. In such cases, the analysis was done using only data from countries that responded, with the number of respondents as the denominator.

Comments on data collection

Participation in the Annual Global Survey is voluntary. Although these data are self-reported, fairly consistent information on hemophilia care has been obtained from countries with similar economic capacities, validating its use for program planning. Some countries are only able to provide detailed data on gender, age, inhibitors and HIV/HCV infection for a limited subset of patients. For example, they may know the total number of people with hemophilia in the country but only have age and gender data from a single treatment centre. This report provides information on the annual usage of treatment products for 2014 only. It includes only those countries where the national hemophilia organization provided information. Quantities reported were not independently verified except when the WFH has data on humanitarian donations it provided in 2014. The amounts reported may only be factor bought through government and not through other sources. Not all national hemophilia organizations are able to report on all products used in their country. Although factor use per capita is a useful way to compare the availability of treatment products between countries, it is not a reflection of how individual patients are treated. For example, in a country with a lower than expected number of identified patients, the amount of treatment product available per patient is higher than the per capita number would suggest.

Please consider the following caveats about the data in this report.

- a) Founder effects can create pockets of patients concentrated geographically. The founder effect occurs when a small population grows in isolation and there is little genetic dilution. This can increase the local frequency of genetic disease compared to the general population. This may occur with hemophilia and all the rare bleeding disorders. In the extremely rare bleeding disorders, consanguinity may lead to an increased incidence in some countries.
- b) Countries with small populations can appear to have too many identified patients. Countries submitting data to the WFH range in population from 300,000 to over a billion. With a small denominator (total population), just a few extra identified patients (the numerator) can create the appearance of huge percentage differences between expected and identified patients when really there are only a few more patients than expected.
- c) The type of health care system in a country can influence data quality. A country with universal health care may be more likely to identify patients with hemophilia even if they don't require treatment. In countries with different health care systems, it is likely that patients who do not require treatment will not be identified.
- d) Definitions may vary from country to country. Countries may use different definitions to diagnose mild hemophilia and other disorders. In the case of the rare bleeding disorders, some countries may report heterozygous patients while other countries report only patients with bleeding symptoms.
- e) Some countries are reporting every patient who seeks treatment while other countries are using methods to identify patients who do not require treatment, such as laboratory screening or follow up with families of identified patients.
- f) Data gathering and the state of registries varies. Maintaining accurate registries can be time consuming and expensive. It is possible that some registries contain patients who have been double-entered or have died. Even wealthy countries with excellent registries have to carefully review their records to avoid over-counting. Countries with large populations are more susceptible to over-counting. It is harder to keep track of births and deaths. Some patients may be registered in more than one treatment centre and validation of registry data is more difficult.
- g) There is also the possibility that the death rate due to HIV and hepatitis C infection is not the same around the world. In some countries there may have been lower infection rates, while other countries may have had better treatment for infected people with hemophilia.
- h) The numbers in this report are as reported by our members. They are not independently verified by the WFH. Some countries are not reporting for the whole country; they only have data from certain treatment centres or large cities.

The Report on the Annual Global Survey is collected under the supervision of the WFH Data & Demographics Committee, including: Alfonso Iorio (chair), Declan Noone (vice chair), Paula Bolton-Maggs, Magdy El Ekiaby, Mike Makris, Suely Rezende, Mike Soucie, Alok Srivastava, Jeff Stonebraker, Marijke van den Berg and Jerzy Windyga.



Report on the Annual Global Survey 2014 summary

Demographics

Number of countries in this survey	106
Percentage of world population covered by countries included in 2014 survey report	91%
Number of people identified with hemophilia	178,500
Number of people identified with von Willebrand disease	69,747
Number of people identified with other bleeding disorders	38,819
Total number of people with bleeding disorders identified	287,066
Number of people with hemophilia A	143,523
Number of people with hemophilia B	28,775
Number of hemophilia A patients with current clinically identified inhibitors	3,242
Number of hemophilia B patients with current clinically identified inhibitors	228

These numbers represent the total number of people identified, not those newly identified in this survey. The total number of patients identified with hemophilia may be higher than the reported sum of people with hemophilia A and B because for some people in some countries, the subtype has not been identified. Some countries included in the report have not surveyed their entire population.

Factor usage

Mean global per capita factor VIII usage	2.25 IU	72 countries
Median global per capita factor VIII usage	1.17 IU	72 countries
Interquartile range (IQR) global per capita factor VIII usage	3.64 IU (0.037 to 3.676)	72 countries
Total reported annual global consumption of factor VIII concentrates	5,233,797,123 IU	72 countries
Mean global per capita factor IX usage	0.35 IU	65 countries
Median global per capita factor IX usage	0.16 IU	65 countries
Interquartile range (IQR) global per capita factor IX usage	0.50 IU (0.07 to 0.507)	65 countries
Total reported annual global consumption of factor IX concentrates	761,480,390 IU	59 countries

The average per capita and total consumption figures reported this year cannot be directly compared to the figures from other survey years as the group of countries reporting factor usage changes from year to year. To illustrate, if a large country using large amounts of factor or a large country using very little factor, reports one year and not the next, then this will have a significant effect on the mean and median from year to year. The interquartile range (IQR) describes the middle 50% of reported numbers and is less likely to be distorted by outliers (extreme values).

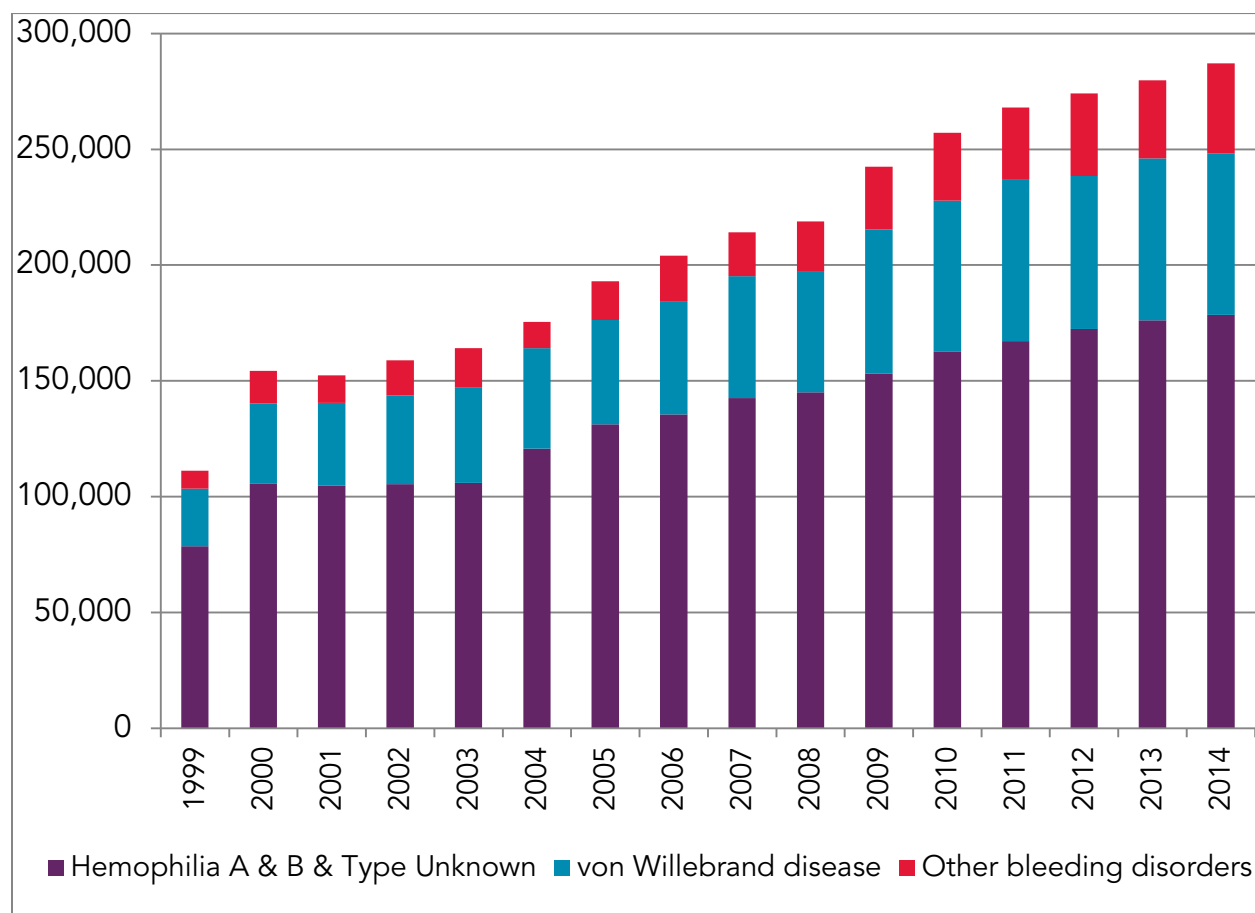
The chart below shows average per capita factor use for the countries that reported in both the 2013 and 2014 surveys.

Factor use in 2013 and 2014

	2013	2014	
Mean global per capita factor VIII usage	2.06 IU	2.28 IU	49 countries reporting
Median global per capita factor VIII usage	1.00 IU	1.22 IU	49 countries reporting
Interquartile range (IQR) global per capita factor VIII usage	3.396 IU (0.044 to 3.44)	3.661 IU (0.07 to 3.731)	49 countries reporting
Mean global per capita factor IX usage	0.36 IU	0.39 IU	43 countries reporting
Median global per capita factor IX usage	0.14 IU	0.19 IU	43 countries reporting
Interquartile range (IQR) global per capita factor IX usage	0.55 IU (0.008 to 0.558)	0.525 IU (0.013 to 0.538)	43 countries reporting



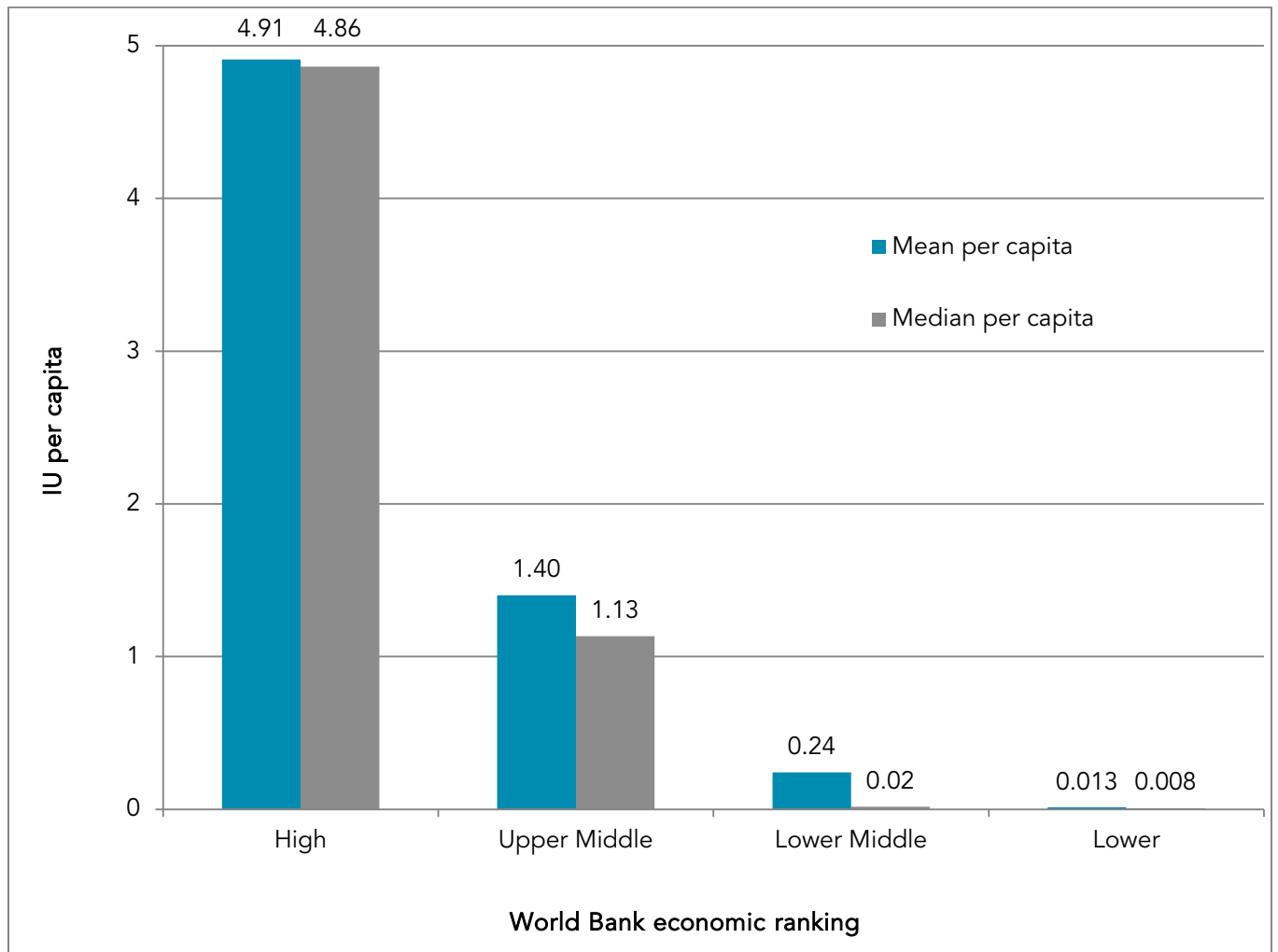
A. Identified patients – all disorders



This graph showing the increase over time in patients identified contains historical data from the Global Survey. This graph was created using aggregated numbers to demonstrate the increases in patients identified over time. If a country reported data one year and not the next, the older data were used on the assumption that the number of patients did not change substantially from one year to the next. For all the graphs, answers are not always available for all questions. In such cases, the graph was created using only data from countries that responded, with the number of respondents as the denominator.

B1. Average global factor VIII use per capita based on World Bank economic rankings

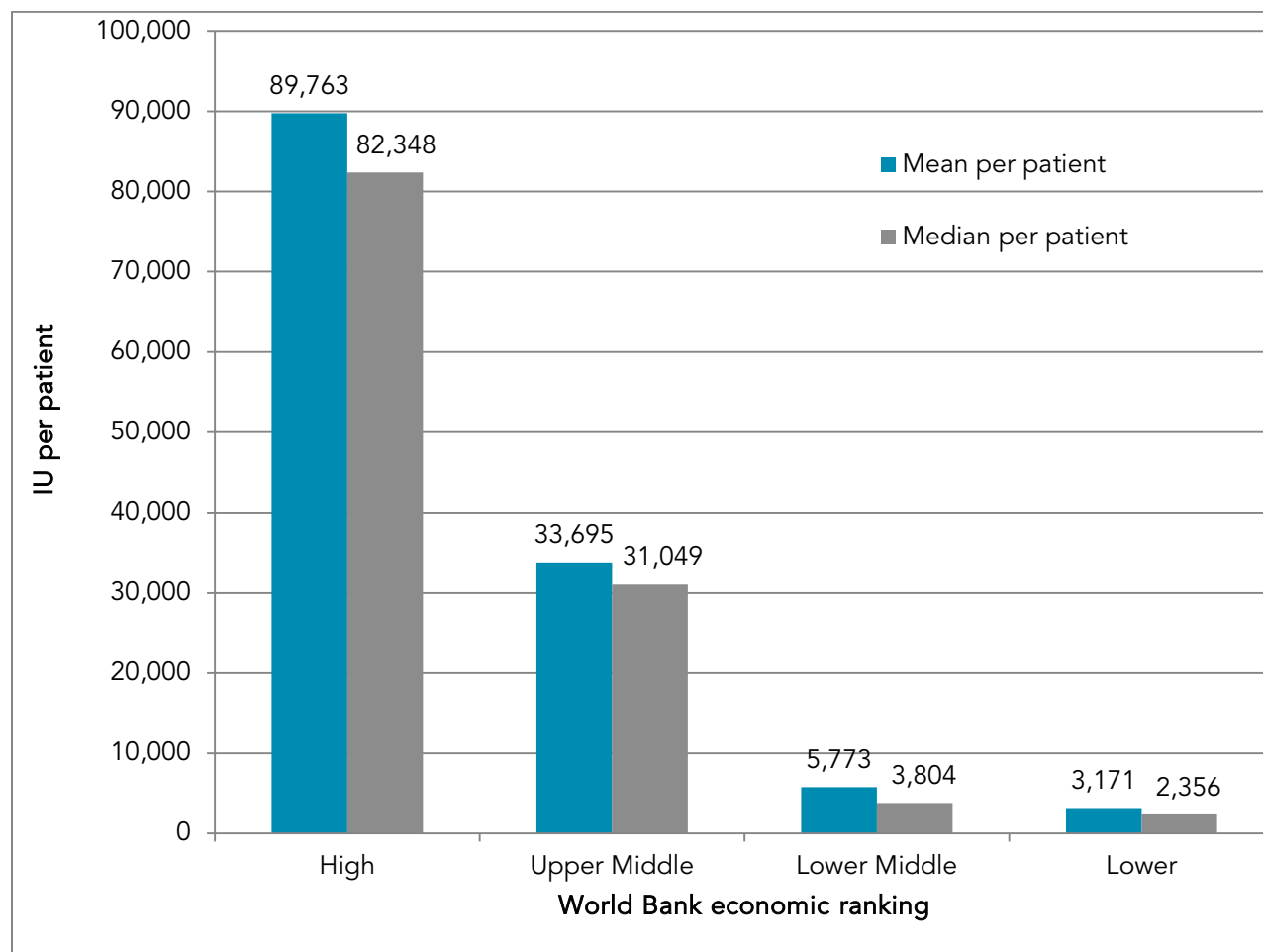
(Data from 72 countries.)



(Gross national income per capita in US dollars: lower income, \$0-\$1,045; lower middle income, \$1,046 - \$4,125; upper middle income, \$4,126 - \$12,735; and high income, \$12,736 or more.)

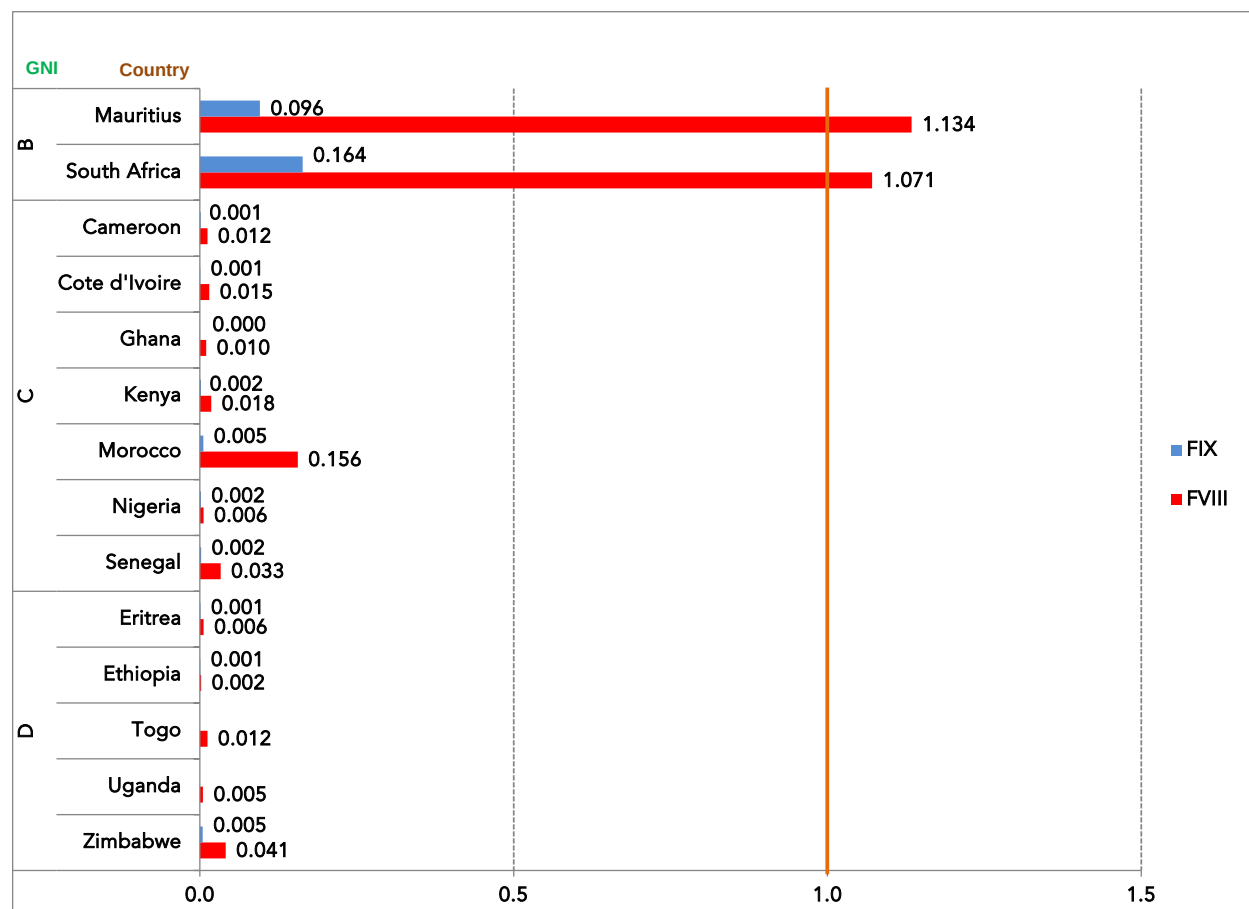
B2. Average global factor VIII use per patient based on World Bank economic rankings

(Data from 72 countries.)



(Gross national income per capita in US dollars: lower income, \$0-\$1,045; lower middle income, \$1,046 - \$4,125; upper middle income, \$4,126 - \$12,735; and high income, \$12,736 or more.)

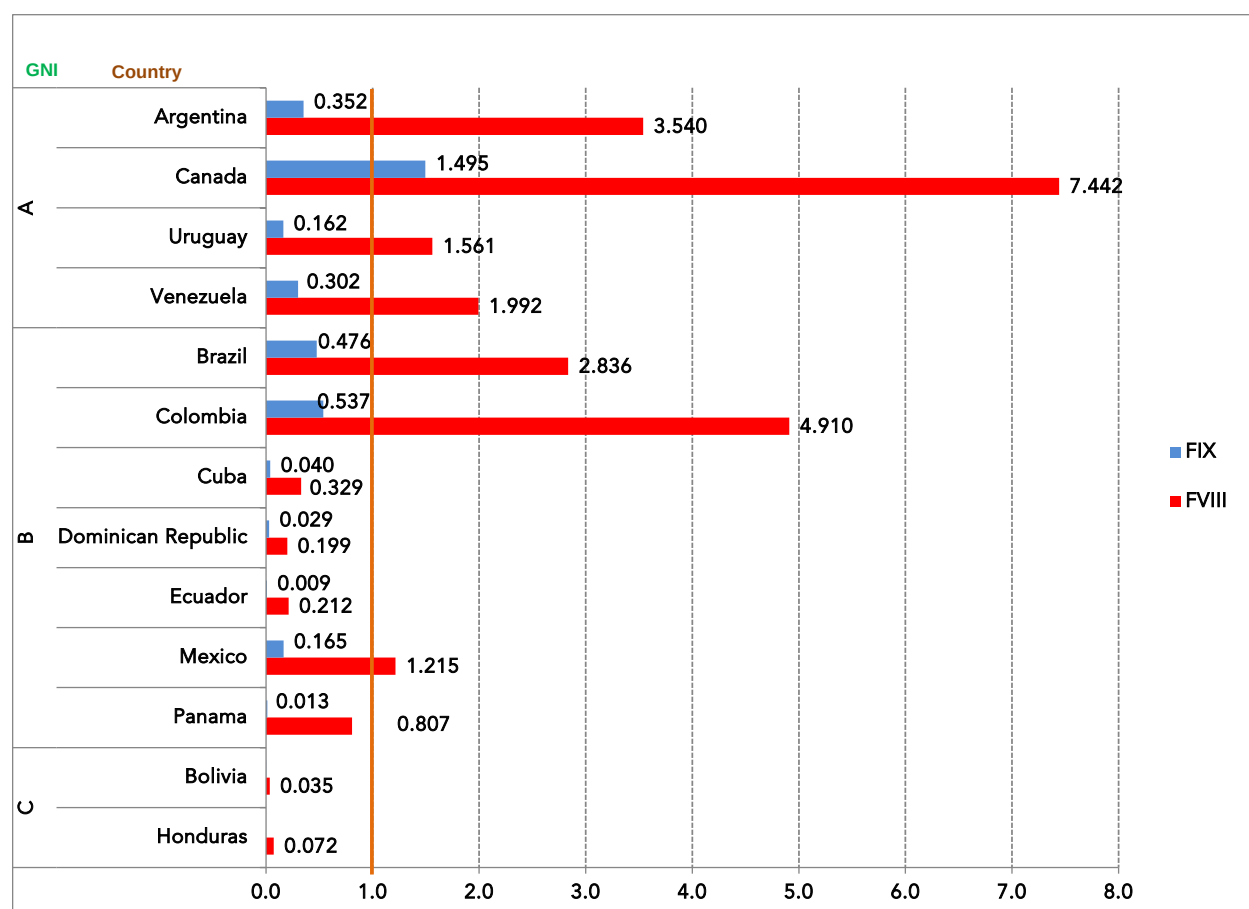
C1. Mean per capita factor VIII and IX use in 2014 – regional and GNI comparisons of IU/total population: Africa



Economic category based on World Bank rankings. Categories are based on the rankings for 2014. (GNI in US dollars: D lower income, \$0-\$1,045; C lower middle income, \$1,046 - \$4,125; B upper middle income, \$4,126 - \$12,735; and A high income, \$12,736 or more.) (Regions based on WHO regions.)

PLEASE NOTE: The X axis showing the number of IU/capita is different in each graph. The orange line indicates 1 IU per capita of factor VIII. The WFH has established that one international unit (IU) of FVIII clotting factor concentrate per capita should be the target minimum for countries wishing to achieve survival for the hemophilia population. Higher levels would be required to preserve joint function or achieve a quality of life equivalent to an individual without hemophilia. Please note the orange line does not apply to factor IX. Where there is no number for factor IX, no data were reported. Only countries that completed the 2014 questionnaire are included in these charts.

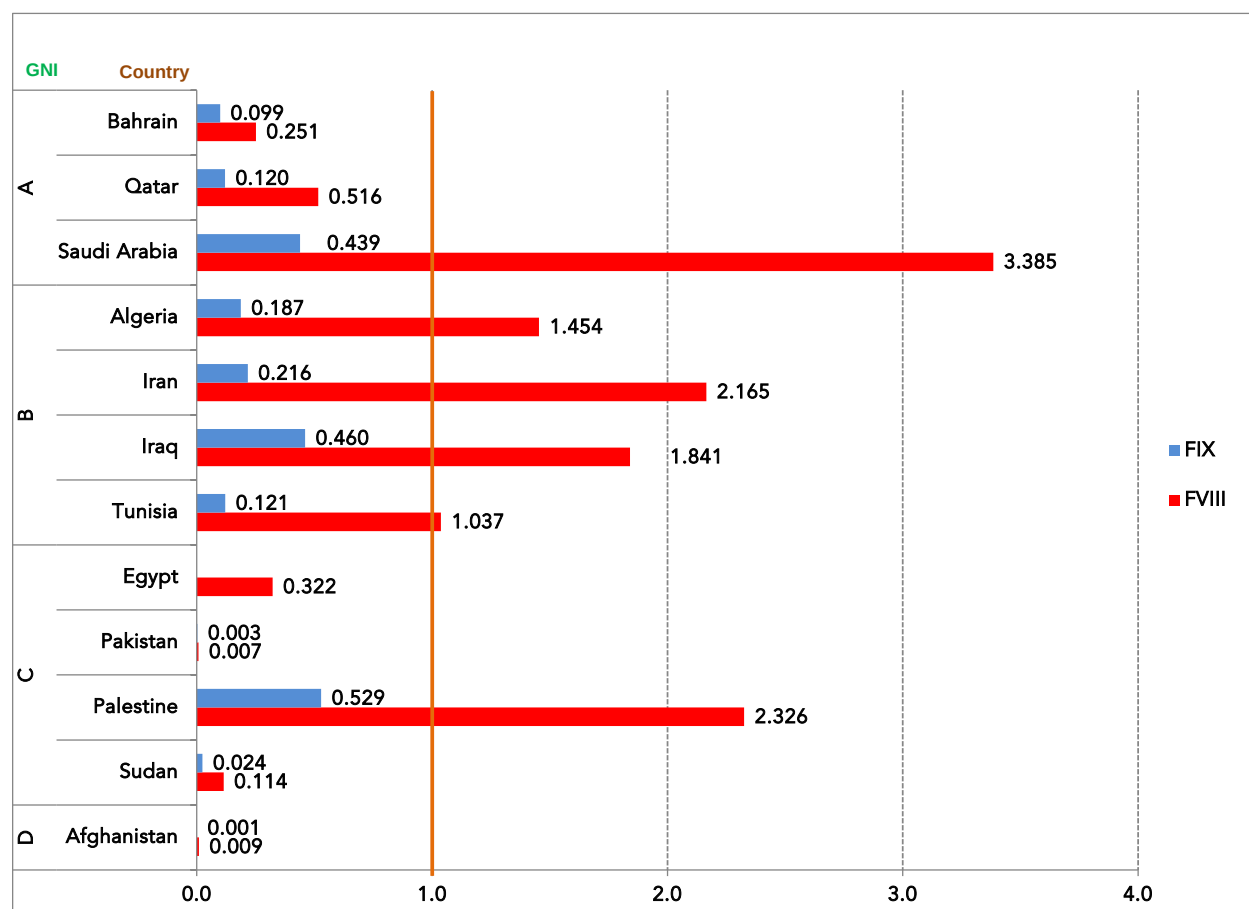
C2. Mean per capita factor VIII and IX use in 2014 – regional and GNI comparisons of IU/total population: Americas



Economic category based on World Bank rankings. Categories are based on the rankings for 2014. (GNI in US dollars: D lower income, \$0-\$1,045; C lower middle income, \$1,046 - \$4,125; B upper middle income, \$4,126 - \$12,735; and A high income, \$12,736 or more.) (Regions based on WHO regions.)

PLEASE NOTE: The X axis showing the number of IU/capita is different in each graph. The orange line indicates 1 IU per capita of factor VIII. The WFH has established that one international unit (IU) of FVIII clotting factor concentrate per capita should be the target minimum for countries wishing to achieve survival for the hemophilia population. Higher levels would be required to preserve joint function or achieve a quality of life equivalent to an individual without hemophilia. Please note the orange line does not apply to factor IX. Where there is no number for factor IX no data were reported. Only countries that completed the 2014 questionnaire are included in these charts.

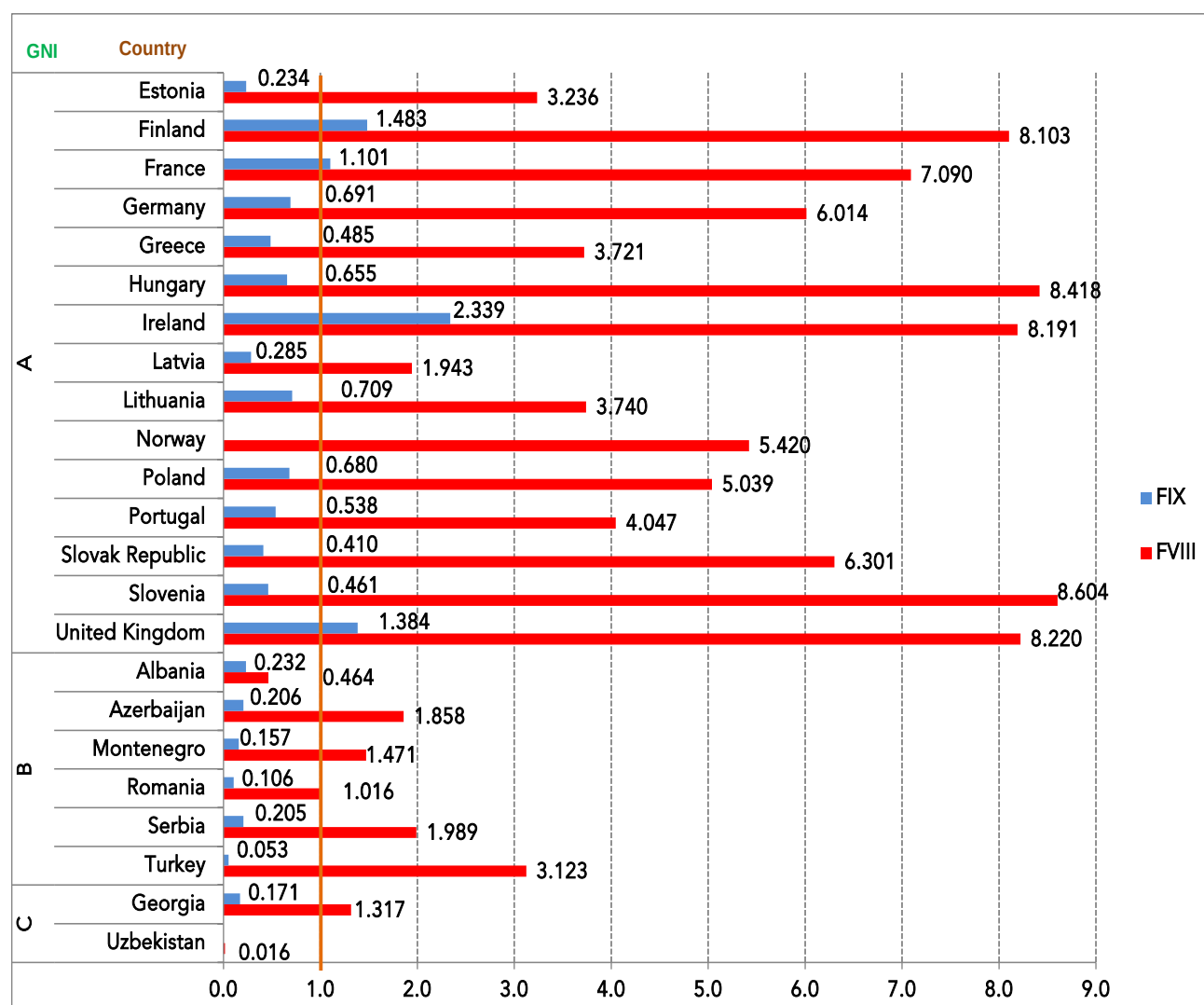
C3. Mean per capita factor VIII and IX use in 2014 – regional and GNI comparisons of IU/total population: Eastern Mediterranean



Economic category based on World Bank rankings. Categories are based on the rankings for 2014. (GNI in US dollars: D lower income, \$0-\$1,045; C lower middle income, \$1,046 - \$4,125; B upper middle income, \$4,126 - \$12,735; and A high income, \$12,736 or more.) (Regions based on WHO regions.)

PLEASE NOTE: The X axis showing the number of IU/capita is different in each graph. The orange line indicates 1 IU per capita of factor VIII. The WFH has established that one international unit (IU) of FVIII clotting factor concentrate per capita should be the target minimum for countries wishing to achieve survival for the hemophilia population. Higher levels would be required to preserve joint function or achieve a quality of life equivalent to an individual without hemophilia. Please note the orange line does not apply to factor IX. Where there is no number for factor IX no data were reported. Only countries that completed the 2014 questionnaire are included in these charts.

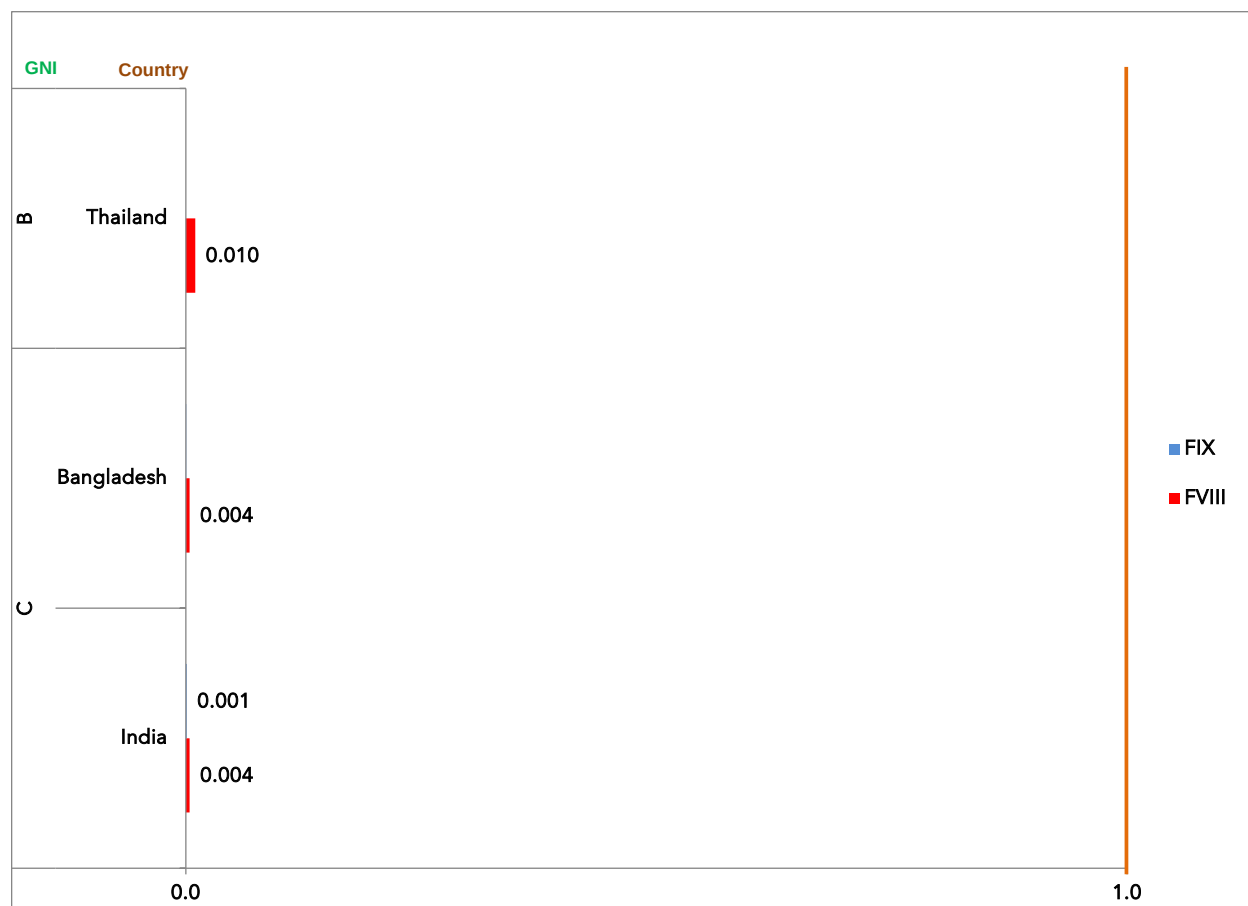
C4. Mean per capita factor VIII and IX use in 2014 – regional and GNI comparisons of IU/total population: Europe



Economic category based on World Bank rankings. Categories are based on the rankings for 2014. (GNI in US dollars: D lower income, \$0-\$1,045; C lower middle income, \$1,046 - \$4,125; B upper middle income, \$4,126 - \$12,735; and A high income, \$12,736 or more.) (Regions based on WHO regions.)

PLEASE NOTE: The X axis showing the number of IU/capita is different in each graph. The orange line indicates 1 IU per capita of factor VIII. The WFH has established that one international unit (IU) of FVIII clotting factor concentrate per capita should be the target minimum for countries wishing to achieve survival for the hemophilia population. Higher levels would be required to preserve joint function or achieve a quality of life equivalent to an individual without hemophilia. Please note the orange line does not apply to factor IX. Where there is no number for factor IX no data were reported. Only countries that completed the 2014 questionnaire are included in these charts.

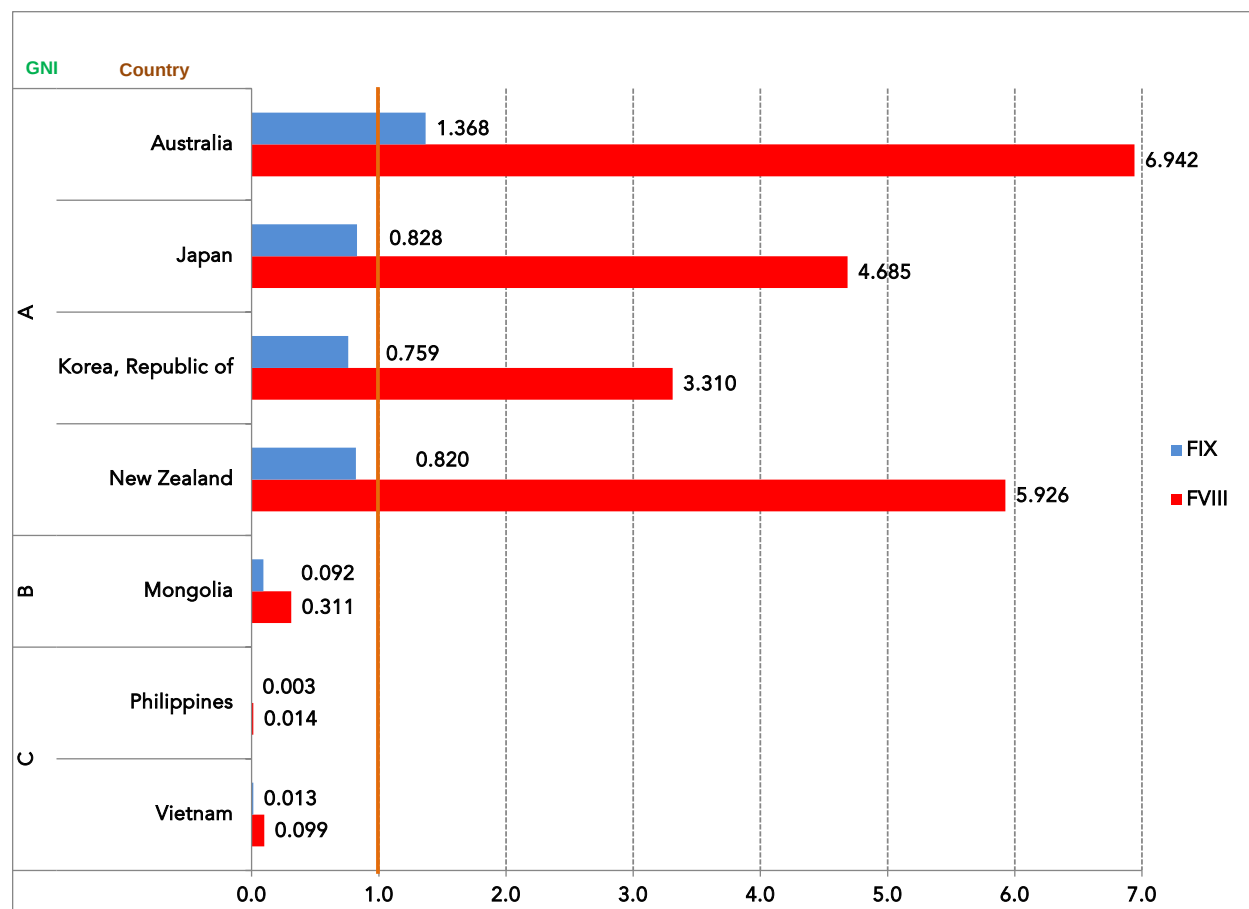
C5. Mean per capita factor VIII and IX use in 2014 – regional and GNI comparisons of IU/total population: South-East Asia



Economic category based on World Bank rankings. Categories are based on the rankings for 2014. (GNI in US dollars: D lower income, \$0-\$1,045; C lower middle income, \$1,046 - \$4,125; B upper middle income, \$4,126 - \$12,735; and A high income, \$12,736 or more.) (Regions based on WHO regions.)

PLEASE NOTE: The X axis showing the number of IU/capita is different in each graph. The orange line indicates 1 IU per capita of factor VIII. The WFH has established that one international unit (IU) of FVIII clotting factor concentrate per capita should be the target minimum for countries wishing to achieve survival for the hemophilia population. Higher levels would be required to preserve joint function or achieve a quality of life equivalent to an individual without hemophilia. Please note the orange line does not apply to factor IX. Where there is no number for factor IX no data were reported. Only countries that completed the 2014 questionnaire are included in these charts.

C6. Mean per capita factor VIII and IX use in 2014 – regional and GNI comparisons of IU/total population: Western Pacific

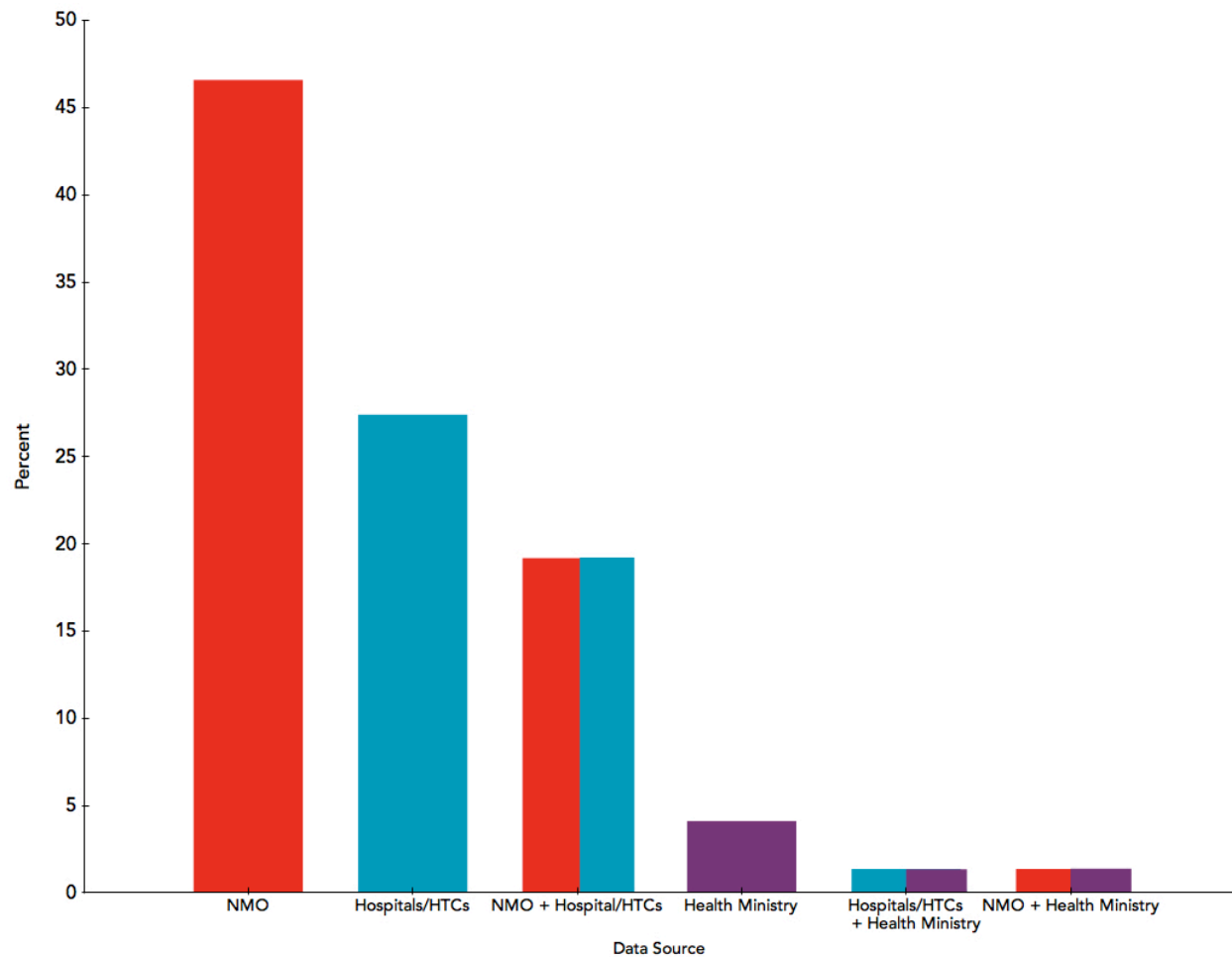


Economic category based on World Bank rankings. Categories are based on the rankings for 2014. (GNI in US dollars: D lower income, \$0-\$1,045; C lower middle income, \$1,046 - \$4,125; B upper middle income, \$4,126 - \$12,735; and A high income, \$12,736 or more.) (Regions based on WHO regions.)

PLEASE NOTE: The X axis showing the number of IU/capita is different in each graph. The orange line indicates 1 IU per capita of factor VIII. The WFH has established that one international unit (IU) of FVIII clotting factor concentrate per capita should be the target minimum for countries wishing to achieve survival for the hemophilia population. Higher levels would be required to preserve joint function or achieve a quality of life equivalent to an individual without hemophilia. Please note the orange line does not apply to factor IX. Where there is no number for factor IX no data were reported. Only countries that completed the 2014 questionnaire are included in these charts.

Data source

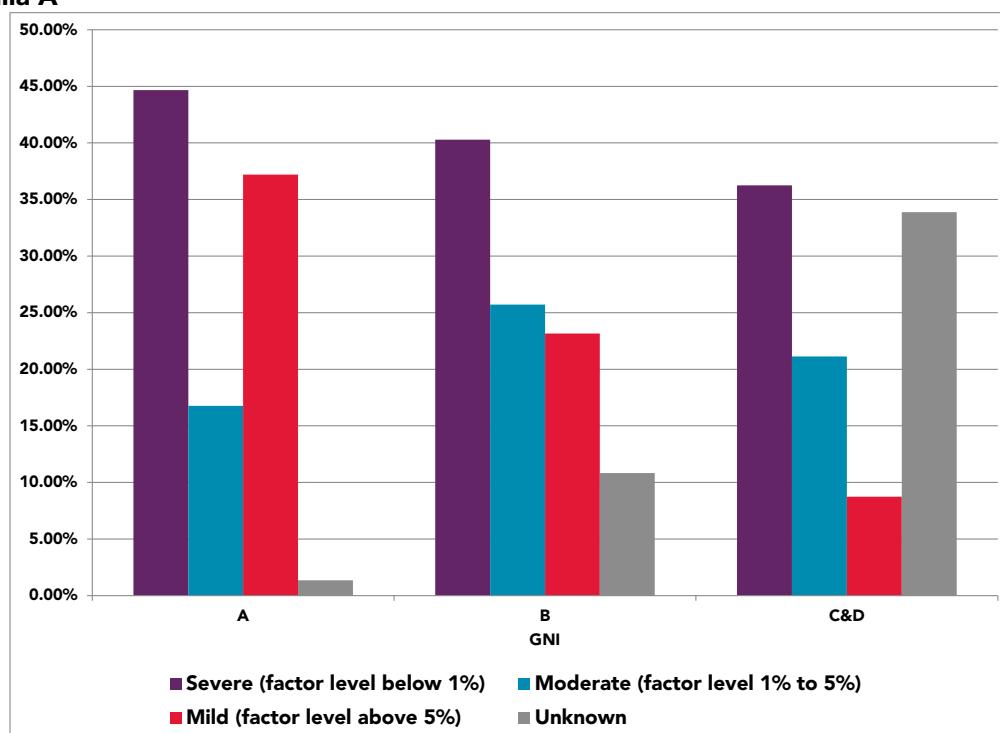
Members were asked the source of the numbers provided for the survey. Possible answers were: Hemophilia Society and/or NMO registry or database, Hospital(s)/HTC(s) registry or database, Health Ministry registry or database or Other. Many members used multiple sources to obtain data.



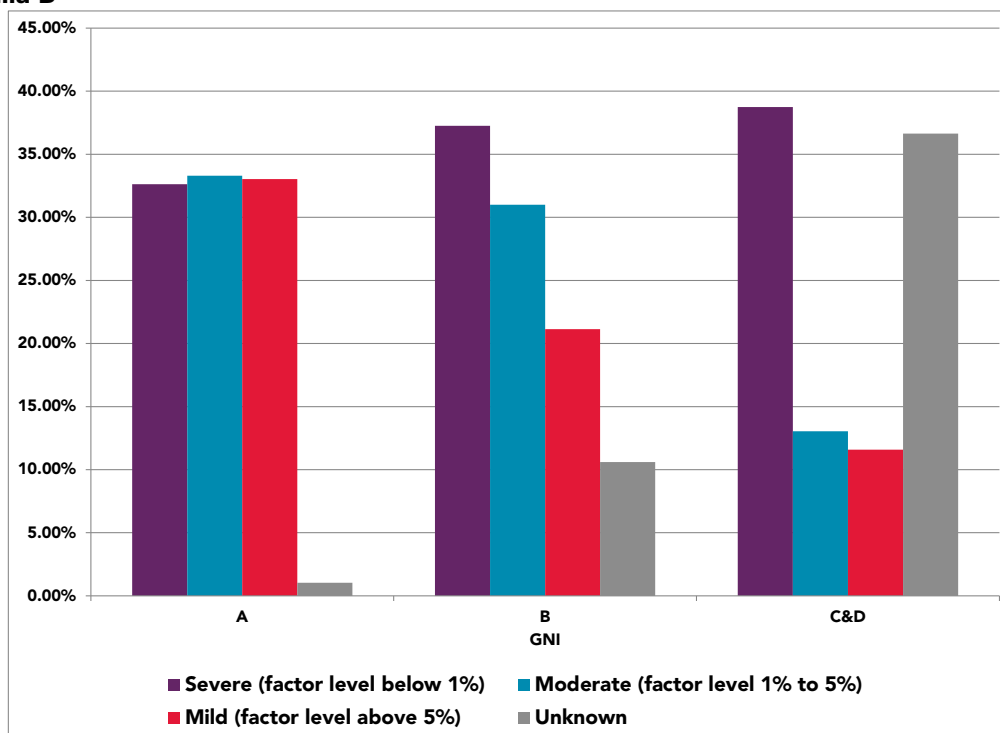
Severity in hemophilia males

There are three levels of severity of hemophilia: mild, moderate and severe. The severity of hemophilia depends on the amount of clotting factor in the person's blood.

Hemophilia A



Hemophilia B



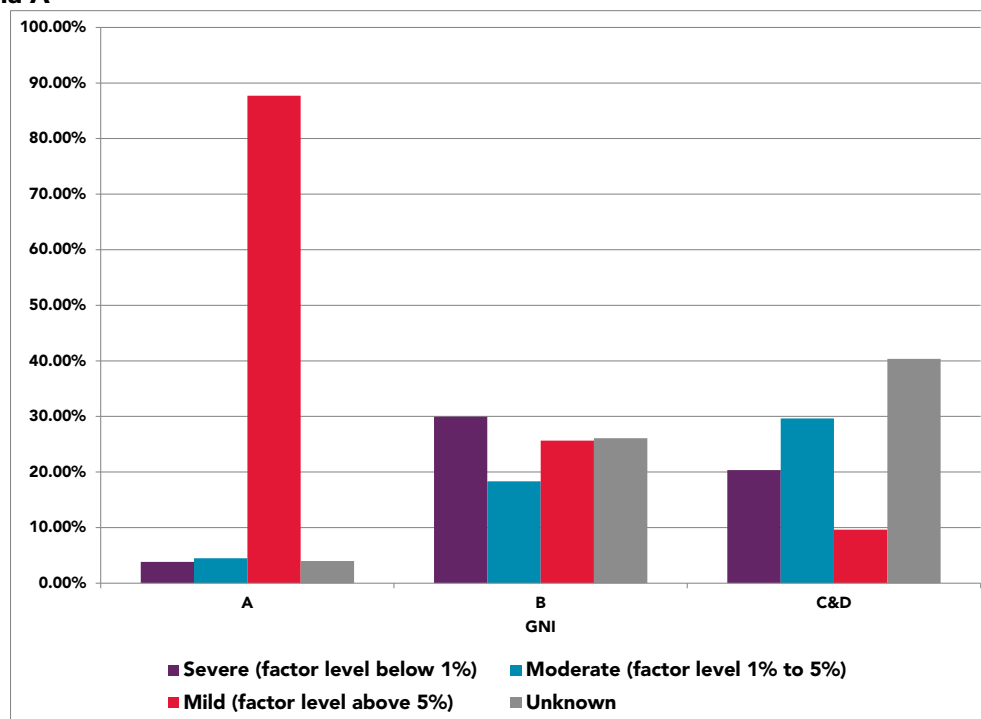
Economic category based on World Bank rankings. Categories are based on the rankings for 2014. (GNI in US dollars: D lower income, \$0-\$1,045; C lower middle income, \$1,046 - \$4,125; B upper middle income, \$4,126 - \$12,735; and A high income, \$12,736 or more.) (Regions based on WHO regions.)



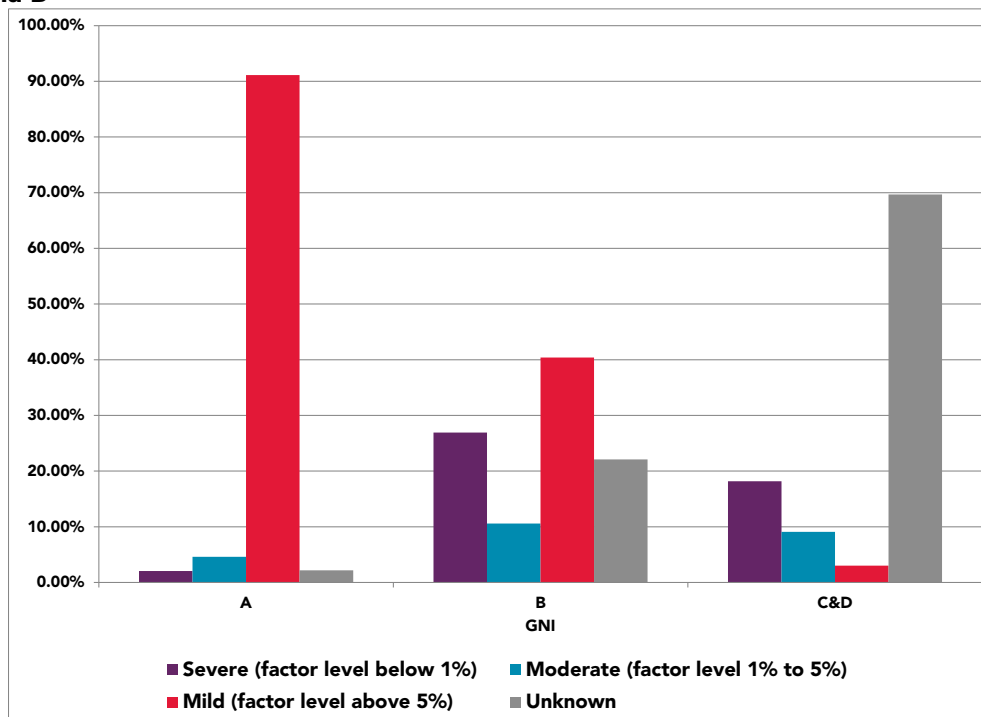
Severity in hemophilia females

There are three levels of severity of hemophilia: mild, moderate and severe. The severity of hemophilia depends on the amount of clotting factor in the person's blood.

Hemophilia A



Hemophilia B



Economic category based on World Bank rankings. Categories are based on the rankings for 2014. (GNI in US dollars: D lower income, \$0-\$1,045; C lower middle income, \$1,046 - \$4,125; B upper middle income, \$4,126 - \$12,735; and A high income, \$12,736 or more.) (Regions based on WHO regions.)

Countries included in the Report on the Annual Global Survey 2014

Please note: the year indicates the year the submitted data applies to. Not all of our members are able to submit data every year. For the 2014 survey report, 82 countries submitted data for 2014. Countries in **BOLD** reported data for 2014.

The data used from other years is as follows: 2013: 13 countries, 2012: 11 countries. 2012 and 2013 surveys are only used for reporting the number of patients identified – all other numbers in this report are from 2014 only.

Afghanistan	2014	Greece	2014	Palestine	2014
Albania	2014	Guatemala	2012	Panama	2014
Algeria	2014	Honduras	2014	Paraguay	2014
Argentina	2014	Hungary	2014	Philippines	2014
Australia	2014	India	2014	Poland	2014
Austria	2014	Indonesia	2012	Portugal	2014
Azerbaijan	2014	Iran	2014	Qatar	2014
Bahrain	2014	Iraq	2014	Romania	2014
Bangladesh	2014	Ireland	2014	Russia	2013
Belarus	2014	Italy	2012	Saudi Arabia	2014
Belgium	2014	Jamaica	2012	Senegal	2014
Belize	2013	Japan	2014	Serbia	2014
Bolivia	2014	Jordan	2014	Slovak Republic	2014
Brazil	2014	Kenya	2014	Slovenia	2014
Cambodia	2014	Korea, Republic of	2014	South Africa	2014
Cameroon	2014	Kyrgyzstan	2013	Spain	2013
Canada	2014	Latvia	2014	Sudan	2014
China	2012	Lebanon	2012	Sweden	2012
Colombia	2014	Lesotho	2014	Switzerland	2012
Costa Rica	2014	Lithuania	2014	Syria	2013
Cote d'Ivoire	2014	Malaysia	2013	Tanzania	2013
Cuba	2014	Maldives	2014	Thailand	2014
Cyprus	2013	Mauritius	2014	Togo	2014
Czech Republic	2013	Mexico	2014	Tunisia	2014
Dominican Republic	2014	Moldova	2012	Turkey	2014
Ecuador	2014	Mongolia	2014	Uganda	2014
Egypt	2014	Montenegro	2014	Ukraine	2013
El Salvador	2012	Morocco	2014	United Kingdom	2014
Eritrea	2014	Nepal	2013	United States	2014
Estonia	2014	Netherlands	2012	Uruguay	2014
Ethiopia	2014	New Zealand	2014	Uzbekistan	2014
Finland	2014	Nicaragua	2013	Venezuela	2014
France	2014	Nigeria	2014	Vietnam	2014
Georgia	2014	Norway	2014	Zimbabwe	2014
Germany	2014	Oman	2013		
Ghana	2014	Pakistan	2014		



Population statistics

(NOTE: In all of the population charts a 0 indicates that the member organization reported the number zero and "Not known" means that the member organization reported that they do not know the answer. Countries in **BOLD** reported data for 2014. For countries that did not report population statistics for 2014 but did report during the years 2012-2013, we used the most recent number of patients reported. 2012 and 2013 surveys are only used for reporting the number of patients identified – all other numbers in this report are from 2014 only.)

Country	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Afghanistan	31,822,848	288	Not Known	Not Known
Albania	3,020,209	150	1	3
Algeria	38,813,722	2,066	153	397
Argentina	43,024,374	2,537	404	21
Australia	22,507,617	2,332	1,896	586
Austria	8,223,062	722	Not Known	Not Known
Azerbaijan	9,686,210	1,201	185	77
Bahrain	1,314,089	28	Not Known	22
Bangladesh	166,280,712	663	2	3
Belarus	9,608,058	584	194	60
Belgium	10,449,361	1,051	1,756	406
Belize	340,844	15	Not Known	Not Known
Bolivia	10,631,486	66	Not Known	Not Known
Brazil	202,656,788	11,497	6,544	1,982
Cambodia	15,458,332	99	1	3
Cameroon	23,130,708	131	10	Not Known
Canada	34,834,841	3,822	4,180	1,899
China	1,355,692,576	11,108	58	261
Colombia	46,245,297	2,149	842	243
Costa Rica	4,755,234	211	71	37
Cote d'Ivoire	22,848,945	73	3	3
Cuba	11,047,251	469	301	2,803
Cyprus	1,172,458	99	75	7
Czech Republic	10,627,448	1,060	710	65
Dominican Rep.	10,349,741	187	29	37
Ecuador	15,654,411	114	40	3
Egypt	86,895,099	5,246	513	1,123
El Salvador	6,125,512	139	39	21
Eritrea	6,380,803	55	Not Known	Not Known
Estonia	1,257,921	104	91	58
Ethiopia	96,633,458	175	21	3
Finland	5,268,799	227	508	Not Known
France	66,259,012	6,601	1,716	457
Georgia	4,935,880	301	31	20
Germany	80,996,685	4,066	2,098	Not Known



Country	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Ghana	25,758,108	73	6	0
Greece	10,775,557	1,003	1,063	352
Guatemala	14,647,083	119	13	1
Honduras	8,598,561	214	3	4
Hungary	9,919,128	1,071	1,423	451
India	1,236,344,631	17,470	489	324
Indonesia	253,609,643	1,593	1	Not Known
Iran	80,840,713	5,724	1,348	2,580
Iraq	32,585,692	1,196	279	313
Ireland	4,832,765	812	1,181	920
Italy	61,680,122	4,529	2,233	1,805
Japan	127,103,388	5,904	1,129	361
Jordan	7,930,491	349	252	246
Kenya	45,010,056	600	42	10
Korea, Rep. of	49,039,986	2,031	107	117
Kyrgyzstan	5,604,212	342	8	Not Known
Latvia	2,165,165	155	120	6
Lebanon	5,882,562	165	104	69
Lesotho	1,942,008	24	Not Known	Not Known
Lithuania	3,505,738	168	302	18
Malaysia	30,073,353	1,300	572	266
Maldives	393,595	9	Not Known	Not Known
Mauritius	1,331,155	51	Not Known	7
Mexico	120,286,655	4,938	256	32
Moldova	3,583,288	224	5	5
Mongolia	2,953,190	78	10	Not Known
Montenegro	650,036	43	3	5
Morocco	32,987,206	1,116	7	Not Known
Nepal	30,986,975	470	3	14
Netherlands	16,877,351	1,210	2,500	46
New Zealand	4,401,916	437	210	42
Nicaragua	5,848,641	225	68	9
Nigeria	177,155,754	203	5	Not Known
Norway	5,147,792	443	880	77
Oman	3,219,775	124	333	325
Pakistan	196,174,380	549	138	65
Palestine	1,816,379	290	33	8
Panama	3,608,431	288	459	54
Paraguay	6,703,860	416	5	1
Philippines	107,668,231	1,229	31	Not Known
Poland	38,346,279	2,717	1,477	616



Country	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Portugal	10,813,834	700	48	16
Qatar	2,123,160	54	35	20
Romania	21,729,871	1,635	111	14
Russia	142,470,272	6,793	1,491	954
Saudi Arabia	27,345,986	389	172	149
Senegal	13,635,927	171	4	7
Serbia	7,209,764	519	267	33
Slovak Republic	5,443,583	589	594	960
Slovenia	1,988,292	210	180	122
South Africa	48,375,645	2,124	623	220
Spain	47,737,941	3,050	Not Known	Not Known
Sudan	35,482,233	866	209	247
Sweden	9,723,809	1,014	1,474	332
Switzerland	8,061,516	701	137	88
Syria	17,951,639	627	63	70
Tanzania	49,639,138	64	Not Known	Not Known
Thailand	67,741,401	402	67	56
Togo	7,351,374	18	Not Known	Not Known
Tunisia	10,937,521	419	119	252
Turkey	81,619,392	5,738	1,119	2,290
Uganda	35,918,915	80	3	Not Known
Ukraine	44,291,413	2,188	469	11
United Kingdom	63,742,977	6,811	10,254	6,633
United States	318,892,103	17,131	11,463	5,241
Uruguay	3,332,972	192	214	32
Uzbekistan	28,929,716	1,432	93	46
Venezuela	28,868,486	2,556	894	944
Vietnam	93,421,835	2,373	73	333
Zimbabwe	13,771,721	116	1	Not Known
Total	6,491,492,078	178,500	69,747	38,819

Distribution of reported bleeding disorders by country

(NOTE: In all of the population charts a 0 indicates that the member organization reported the number zero, a blank space indicates that no number was reported. Countries in **BOLD** reported data for 2014.)

Country	Hemophilia A	Hemophilia B	Hemophilia type unknown	VWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXIII	Bleeding Disorder: Type Unknown	Glanzmanns thrombasthenia	Bernard Soulier	Platelet disorders: Other/Unknown
Afghanistan	273	15														
Albania	132	18		1				1	1			1				
Algeria	1,725	341		153	31	4	27	18	248	15	8	17		19	10	
Argentina	2,220	317	0	404				1	2		1			2		15
Australia	1,868	464	0	1,896	40	0	10	0	56	18	199	19	11	15	4	214
Austria	607	115														
Azerbaijan	1,072	129		185		2	6	16	13	11	8	4		6	11	
Bahrain	24	4	0		0	3	2	2	1	5	0	3	0	6		
Bangladesh	564	93	6	2	2							1				
Belarus	475	109		194	1	0	0		19	22			18			
Belgium	849	195	7	1,756	1	2	23		100	6	113	4	31	19	2	105
Belize	10	5														
Bolivia	57	9														
Brazil	9,616	1,881		6,544	86	13	157	27	723	88	165	61		244	59	359
Cambodia	84	15		1								1		2		
Cameroon	118	13		10												
Canada	3,110	712		4,180	89	13	71	4	329	37	397	55	61	61	29	753
China	9,675	1,433		58			2		2	1	2	1				
Colombia	1,600	361	188	842	16	2	11	2	52	1	33	24	60	9	2	31
Costa Rica	178	33		71	1	0	1	0	18	8	6	3				
Cote d'Ivoire	67	6	0	3	0	0	0	0	1	2	0	0	0	0	0	0
Cuba	401	68	0	301	2	1	2	0	1	0	16	7	21	3	0	2,750
Cyprus	43	56		75	3									4		
Czech Rep.	924	136	0	710	0	2	5	0	26	3	17	2	10			
Dominican Rep.	161	26		29								3	31	3		
Ecuador	107	7	0	40	0	0	1	0	0	0	0	1	0	1	0	0
Egypt	4,201	1,045		513	138	8	165	8	118	106	92	35		439	14	
El Salvador	120	19	0	39	0	0	0		2	1	5	0				
Eritrea	53	2														
Estonia	94	10		91			2	1	30		5		15		1	4
Ethiopia	70	8	97	21										2	1	
Finland	141	30	56	508												
France	5,400	1,201	0	1,716	40	1	49	13	150	22	157	25	0			
Georgia	255	46		31					8			2	7	3		
Germany	3,422	644		2,098												
Ghana	66	7	0	6	0	0	0	0	0	0	0	0	0	0	0	0



Country	Hemophilia A	Hemophilia B	Hemophilia type unknown	VWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXIII	Bleeding Disorder: Type Unknown	Glanzmanns thrombasthenia	Bernard Soulier	Platelet disorders: Other/Unknown
Greece	829	174	0	1,063	12	2	22	0	115	8	87	13	0	15	13	65
Guatemala	109	10		13					1				1	1		
Honduras	189	25		3					2		1	1				
Hungary	850	221		1,423	16	1	22	0	290	20	73	2		5	0	22
India	14,450	2,281	739	489	13	7	48	4	40	27	29	78	20	39	19	
Indonesia	477	66	1,049	1									1			
Iran	4,642	988	94	1,348	125	23	170	211	559	156	180	217	54	522	89	274
Iraq	886	310		279	46	2	8	4	67	20	12	41				113
Ireland	583	229	0	1,181	0	0	143	0	127	123	203	12	0	11	3	298
Italy	3,779	750	0	2,233	0	20	132	30	595	96	372	41	59			207
Jamaica																
Japan	4,870	1,034		1,129	67	8	35	9	91	20	37	68	26			
Jordan	267	82		252		4	13		46	25	42	12		103	1	
Kenya	490	110		42												10
Korea, Rep. of	1,635	396		107	10		7	9	42	3	22	8	16			
Kyrgyzstan																
Latvia	129	26	0	120					5				1			
Lebanon	130	35	0	104	34	0	9	1	7	5	5	2	0	1	0	5
Lesotho	22	2														
Lithuania	145	22	1	302					11	2	3	2				
Malaysia	1,109	191	0	572	4	3	19	1	47	22	51	18	0	49	1	51
Maldives	7	2														
Mauritius	46	5							3	1	1					2
Mexico	3,993	608	337	256	1	0	2	0	18	3	3	1	2	1	0	1
Moldova	207	17		5					1		4					
Mongolia	59	17	2	10												
Montenegro	38	5	0	3	0	0	0	0	1	0	1	3	0	0	0	0
Morocco	904	180	32	7												
Nepal	404	69	5	3		1	1		1	7		1				
Netherlands	1,026	184		2,500	0	2	4		9	0	1	11	3	16		
New Zealand	357	80	0	210	2	1	0	0	7	1	3	4	8	2	1	13
Nicaragua	198	27		68	6								1	2		
Nigeria	199	4	0	5												
Norway	344	99	0	880	2	1	3	0	27	0	1	4	0	10	3	26
Oman	116	8		333	4	1	19	6	58	5	25	1	19	26	2	159
Pakistan	469	80	0	138	3	2	12	14	9	12	0	7	1	0	0	5
Palestine	177	40	73	33		3						2		3		
Panama	256	32	0	459	0	0	0	0	9	16	0	0	0	5	1	23
Paraguay	400	10	1	5									1			
Philippines	1,027	161	41	31												

Country	Hemophilia A	Hemophilia B	Hemophilia type unknown	VWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXIII	Bleeding Disorder: Type Unknown	Glanzmanns thrombasthenia	Bernard Soulier	Platelet disorders: Other/Unknown
Poland	2,311	406		1,477	82		26	3	231	21	51	10		21	6	165
Portugal	538	111	51	48	2	0	3	0	2	1	7			1		
Qatar	40	4	10	35					2			3	9	6		
Romania	1,438	197		111	1			2	2	2	2		1		1	
Russia	5,801	992		1,491									954			
Saudi Arabia	314	75	0	172	1	11	6	1	12	4	10	33	0	67	4	0
Senegal	156	15	0	4	0	0	1	0	3	0	0	0	0	0	0	3
Serbia	441	78		267	4		1	2	14		7	3	1		1	
Slovak Rep.	517	72	0	594	78	0	71	2	673	35	50	3	0	10	15	23
Slovenia	188	22	0	180	0	0	12	2	15	2	18	1	0	7	0	65
South Africa	1,772	352	0	623	8	0	44	5	19	9	29	8	6	17	25	50
Spain																
Sudan	728	138		209	26		35	1	22	24	3	25		105	3	3
Sweden	817	197		1,474		4	1	1	227	20	63	7	1	8	6	250
Switzerland	587	117	0	137	18	0	4	4	29	4	18	14	0	0	0	0
Syria	562	65		63	14		5	28	9	3				11		
Tanzania	34	7	22													
Thailand	346	56		67				1	14	2				39		
Togo	13	5	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Tunisia	330	89		119	31	0	11	5	49	5	22	25	4	80	10	10
Turkey	4,860	878		1,119			29	1	850	164	51	180	969			46
Uganda	71	9		3												
Ukraine	1,860	328		469										1		
United Kingdom	5,646	1,165	0	10,254	509	9	178	26	1,016	216	2,562	64	0	120	79	1,854
United States	13,010	4,121	0	11,463	116	33	211	11	847	101	504	112	0	152	30	3,124
Uruguay	173	19		214	1		1	2	7	2	10		3			6
Uzbekistan	1,296	136		93	1	2			8		9			12	1	13
Venezuela	2,020	536	0	894	19	65	33	27	149	107	361	16	2	15	4	146
Vietnam	1,951	419	3	73	6	3	3	10	21	15	7	5	51	68		144
Zimbabwe	103	13	0	1												
Total	143,523	28,775	2,814	69,739	1,712	259	1,878	516	8,309	1,655	6,164	1,327	2,479	2,389	451	11,407



Gender distribution

This table provides the number of males and females with each bleeding disorder from the countries that have that data.

Disorder	Countries reporting	Total patients identified	Male	Percent male	Female	Percent female	Gender not known	Percent not known
Hemophilia A	103	143,523	124,421	87	2,833	2	16,269	11
Hemophilia B	103	28,775	25,024	87	984	3	2,767	10
Hemophilia type unknown	53	2,814	2,521	90	180	6	113	4
Von Willebrand disease	93	69,739	23,613	34	36,768	53	9,358	13
Factor I deficiency	59	1,712	682	40	855	50	175	10
Factor II deficiency	54	259	124	48	116	45	19	7
Factor V deficiency	61	1,878	770	41	911	49	197	10
Factor V+VIII deficiency	58	516	280	54	207	40	29	6
Factor VII deficiency	74	8,309	4,071	49	3,858	46	380	5
Factor X deficiency	63	1,655	724	44	766	46	165	10
Factor XI deficiency	63	6,137	2,661	43	3,245	53	231	4
Factor XIII deficiency	65	1,327	731	55	500	38	96	7
Bleeding disorder: type unknown	56	2,479	1,029	42	387	16	1,063	43
Platelet disorders: Glanzmanns thrombasthenia	59	2,389	825	35	836	35	728	30
Platelet disorders: Bernard Soulier syndrome	46	451	201	45	220	49	30	7
Platelet disorders: other or unknown	46	11,407	3,893	34	7,090	62	424	4

A woman who has less than 40 per cent of the normal level of clotting factor is no different from a man with the same factor levels – she has hemophilia.

Number of prevalent and incident cases of inhibitors in Hemophilia A and B

Patients with current clinically significant inhibitors, meaning, patients who do not respond to standard treatment.

Country	Hemophilia A inhibitors (total)	Hemophilia A Inhibitors (new cases in 2014)	Hemophilia B inhibitors (total)	Hemophilia B Inhibitors (new cases in 2014)
Albania	0	0	0	0
Algeria	41	9	0	No data
Argentina	96	6	6	0
Australia	76	No data	0	0
Austria	23	No data	1	No data
Azerbaijan	20	3	No data	No data
Bahrain	0	0	0	0
Bangladesh	1	0	No data	No data
Belarus	47	No data	5	No data
Bolivia	1	1	No data	No data
Brazil	483	90	43	1
Cambodia	No data	2	No data	No data
Cameroon	7	0	1	0
Canada	68	No data	3	No data
Colombia	74	5	5	0
Costa Rica	19	1	1	0
Cote d'Ivoire	0	0	0	0
Cuba	36	2	0	0
Dominican Republic	10	6	0	0
Ecuador	1	3	0	0
Egypt	40	12	2	No data
Eritrea	No data	2	No data	No data
Estonia	4	1	No data	No data
Finland	12	No data	1	No data
France	102	5	2	0
Georgia	8	1	0	0
Germany	127	No data	10	No data
Ghana	1	1	0	0
Greece	25	3	4	0
Honduras	2	No data	No data	No data
Hungary	49	12	1	0
Iran	232	21	15	0
Iraq	60	10	3	1
Ireland	12	2	2	0
Japan	93	No data	20	No data
Jordan	18	1	1	0
Kenya	2	1	0	0
Korea, Republic of	50	2	6	0
Latvia	2	0	2	0
Lithuania	7	2	0	0
Mauritius	0	0	0	0
Mexico	214	20	13	1



Country	Hemophilia A inhibitors (total)	Hemophilia A Inhibitors (new cases in 2014)	Hemophilia B inhibitors (total)	Hemophilia B Inhibitors (new cases in 2014)
Montenegro	1	1	0	0
Morocco	70	13	25	2
New Zealand	22	No data	0	0
Nigeria	1	0	0	0
Norway	13	1	0	0
Pakistan	5	5	0	0
Panama	6	2	0	0
Paraguay	1	No data	No data	No data
Philippines	11	3	1	0
Poland	149	No data	4	No data
Saudi Arabia	44	No data	2	No data
Senegal	5	0	0	0
Serbia	20	3	0	0
Slovak Republic	7	2	0	0
Slovenia	2	0	0	0
South Africa	163	11	10	1
Sudan	9	0	1	0
Thailand	52	5	1	0
Tunisia	10	No data	No data	No data
Turkey	154	28	18	3
United Kingdom	220	33	10	0
Uruguay	3	1	1	0
Uzbekistan	35	No data	No data	No data
Venezuela	97	4	3	0
Vietnam	76	47	5	5
Zimbabwe	3	2	0	0
Total	3,242	385	228	14

Age distribution: Hemophilia A (73 countries reported age data.)

Country	Hemophilia A	0-4	5-13	14-18	19-44	45+	Age Not Known
Afghanistan	273	19%	43%	15%	22%	1%	
Albania	132			34%			66%
Argentina	2,220	4%	17%	10%	45%	21%	3%
Australia	1,868	6%	15%	8%	40%	32%	
Austria	607	2%	10%	9%	43%	35%	
Azerbaijan	1,072	6%	15%	17%	54%	9%	
Bahrain	24	21%	17%	17%	42%	4%	
Bangladesh	564	6%	30%	24%	35%	5%	
Belarus	475	3%	12%	7%	51%	27%	
Belgium	849	2%	14%	7%	38%	39%	
Bolivia	57	19%	33%	14%	30%	4%	
Brazil	9,616	6%	17%	12%	49%	17%	
Cambodia	84	13%	45%	19%	23%		
Cameroon	118	12%	37%	14%	29%	8%	
Canada	3,110	4%	14%	8%	41%	33%	
Colombia	1,600	8%	19%	11%	29%	11%	23%
Costa Rica	178	6%	20%	13%	45%	10%	6%
Cote d'Ivoire	67	19%	21%	34%	19%	6%	
Cuba	401	2%	12%	9%	54%	23%	
Dominican Republic	161	12%	25%	20%	40%	4%	
Ecuador	107		4%	7%	70%	17%	2%
Egypt	4,201	37%	6%	2%	9%	1%	45%
Eritrea	53	6%	15%	28%	49%	2%	
Estonia	94	5%	9%	6%	61%	19%	
Ethiopia	70	4%	40%	19%	27%	3%	7%
France	5,400	5%	15%	9%	42%	28%	
Georgia	255	7%	17%	7%	47%	21%	
Ghana	66	24%	52%	5%	18%	2%	
Greece	829	3%	10%	6%	41%	41%	
Honduras	189	12%	36%		69%		
Hungary	850	3%	10%	6%	42%	39%	
India	14,450	3%	16%	11%	33%	6%	31%
Iran	4,642	4%	14%	8%	58%	17%	
Iraq	886	23%	37%	19%	18%	3%	
Ireland	583	10%	17%	9%	38%	27%	
Kenya	490	29%	29%	16%	9%	13%	4%
Korea, Republic of	1,635	4%	12%	10%	55%	18%	
Latvia	129	8%	12%	7%	46%	26%	2%
Lesotho	22		27%	41%	32%		
Maldives	7	14%	29%		43%	14%	
Mauritius	46	7%	22%	20%	30%	22%	
Mexico	3,993	2%	16%	11%	44%	10%	17%
Mongolia	59	10%	29%	5%	49%	7%	
Montenegro	38	5%	18%	13%	34%	29%	



Country	Hemophilia A	0-4	5-13	14-18	19-44	45+	Age Not Known
Morocco	904	31%	8%	14%	31%	11%	5%
New Zealand	357	6%	18%	10%	38%	21%	6%
Nigeria	199	16%	40%	13%	28%	1%	3%
Pakistan	469	5%	35%	38%	18%	3%	
Palestine	177	4%	28%	17%	44%	7%	
Panama	256	6%	16%	7%	53%	18%	
Paraguay	400	18%	4%	10%	47%	23%	
Philippines	1,027	6%	22%	18%	37%	6%	11%
Poland	2,311	1%	7%	5%	52%	35%	
Portugal	538	1%	9%	7%	41%	32%	8%
Qatar	40	18%	20%	38%	25%		
Saudi Arabia	314	24%	39%	18%	19%		
Senegal	156	15%	38%	12%	33%	3%	
Serbia	441	3%	13%	7%	46%	31%	
Slovak Republic	517	4%	8%	4%	50%	34%	
Slovenia	188	4%	9%	3%	45%	39%	
South Africa	1,772	5%	17%	10%	44%	21%	3%
Sudan	728	17%	33%	16%	32%	3%	
Thailand	346	2%	12%	14%	69%	3%	
Togo	13	15%	31%	8%	46%		
Turkey	4,860	6%	20%	13%	47%	14%	
Uganda	71	28%	31%	13%	18%	10%	
United Kingdom	5,646	7%	13%	8%	38%	34%	
United States	13,010	9%	23%	13%	38%	17%	
Uruguay	173	6%	12%	9%	66%	7%	
Uzbekistan	1,296	4%	19%	12%	58%	7%	
Venezuela	2,020	4%	15%	9%	41%	15%	15%
Vietnam	1,951	12%	19%	12%	45%	8%	4%
Zimbabwe	103	9%	17%	24%	38%	4%	9%

Age distribution: Hemophilia B (72 countries reported age data.)

Country	Hemophilia B	0-4	5-13	14-18	19-44	45+	Age Not Known
Afghanistan	15	20%	33%	20%	27%		
Albania	18			17%			83%
Argentina	317	5%	21%	10%	44%	18%	2%
Australia	464	4%	14%	6%	42%	34%	
Austria	115	3%	15%	8%	40%	35%	
Azerbaijan	129	8%	13%	21%	42%	16%	
Bahrain	4				100%		
Bangladesh	93	9%	38%	27%	25%	2%	
Belarus	109	5%	12%	6%	55%	22%	
Belgium	195	4%	11%	5%	37%	43%	1%
Bolivia	9	11%	33%		56%		
Brazil	1881	5%	17%	13%	47%	18%	
Cambodia	15	20%	47%	7%	27%		
Cameroon	13	15%	38%	15%	23%	8%	
Canada	712	4%	11%	6%	42%	38%	
Colombia	361	4%	28%	13%	36%	19%	
Costa Rica	33	6%	15%	9%	55%	12%	
Cote d'Ivoire	6	17%	17%	17%	33%	17%	
Cuba	68	1%	9%	6%	53%	31%	
Dominican Republic	26	8%	19%	15%	58%		
Ecuador	7			14%	86%		
Egypt	1045	33%	5%	2%	7%	1%	51%
Eritrea	2				100%		
Estonia	10	10%	30%		30%	30%	
Ethiopia	8	13%	13%	25%	38%	13%	
France	1201	4%	17%	10%	41%	27%	
Georgia	46	9%	13%	7%	50%	22%	
Ghana	7	14%	71%		14%		
Greece	174	3%	6%	4%	43%	44%	
Hungary	221	2%	5%	11%	41%	41%	
India	2281	3%	14%	13%	34%	7%	29%
Iran	988	3%	11%	9%	61%	16%	
Iraq	310	18%	35%	22%	18%	7%	
Ireland	229	7%	17%	8%	40%	28%	
Kenya	110	14%	23%	32%	26%	4%	2%
Korea, Republic of	396	6%	16%	12%	47%	19%	
Latvia	26	8%	12%	8%	58%	15%	
Lesotho	2	50%	50%				
Maldives	2	50%		50%			
Mauritius	5		40%	20%	40%		
Mexico	608	2%	15%	13%	46%	11%	14%
Mongolia	17	24%	24%	24%	29%		
Montenegro	5		20%	20%	20%	20%	20%
Morocco	180	31%	16%	6%	21%	16%	11%



Country	Hemophilia B	0-4	5-13	14-18	19-44	45+	Age Not Known
New Zealand	80	4%	14%	5%	41%	29%	8%
Nigeria	4	50%		25%	25%		
Pakistan	80	9%	31%	44%	13%	1%	3%
Palestine	40		40%	15%	33%	13%	
Panama	32	9%	22%	16%	47%	6%	
Paraguay	10	50%			50%		
Philippines	161	5%	22%	17%	38%	8%	10%
Poland	406	1%	8%	5%	52%	32%	1%
Portugal	111		10%	6%	41%	35%	8%
Qatar	4		25%	50%	25%		
Saudi Arabia	75	15%	43%	5%	37%		
Senegal	15	13%	53%	20%	7%	7%	
Serbia	78	6%	21%	9%	42%	22%	
Slovak Republic	72	7%	11%	10%	42%	31%	
Slovenia	22		5%		55%	41%	
South Africa	352	9%	19%	9%	41%	22%	1%
Sudan	138	19%	41%	14%	25%	1%	
Thailand	56	7%	21%	32%	32%	7%	
Togo	5	40%	40%	20%			
Turkey	878	6%	21%	14%	45%	14%	
Uganda	9	11%	22%	22%	44%		
United Kingdom	1165	8%	12%	7%	41%	32%	
United States	4121	9%	22%	13%	35%	21%	
Uruguay	19	16%	11%	21%	37%	16%	
Uzbekistan	136	4%	21%	17%	53%	5%	
Venezuela	536	2%	13%	8%	39%	19%	18%
Vietnam	419	11%	16%	11%	42%	17%	4%
Zimbabwe	13	15%	8%	8%	54%	8%	8%

Age distribution: Hemophilia Type Unknown (14 countries reported age data.)

Country	Hemophilia Type Unknown	0-4	5-13	14-18	19-44	45+	Age Not Known
Bangladesh	6			100%			
Belgium	7				71%	14%	14%
Colombia	188			1%	6%	16%	77%
Ethiopia	97	5%	44%	16%	34%		
India	739	2%	6%	5%	20%	5%	62%
Iran	94	5%	17%	10%	49%	19%	
Mexico	337	1%	8%	4%	22%	4%	62%
Mongolia	2		50%				50%
Morocco	32	47%				53%	
Palestine	73	5%	59%	15%	18%	3%	
Paraguay	1	100%					
Philippines	41		10%	5%	17%	2%	66%
Portugal	51		2%	6%	22%	27%	43%
Vietnam	3			33%	67%		



Age distribution: VWD (58 countries reported age data.)

Country	VWD	0-4	5-13	14-18	19-44	45+	Age Not Known
Argentina	404		3%	3%	49%	31%	14%
Australia	1896	2%	11%	8%	43%	36%	
Azerbaijan	185	12%	15%	21%	24%	29%	
Bangladesh	2	50%			50%		
Belarus	194		6%	6%	67%	20%	1%
Belgium	1756	1%	17%	9%	43%	28%	1%
Brazil	6544	1%	11%	11%	51%	24%	
Cambodia	1		100%				
Cameroon	10		20%	10%	60%	10%	
Canada	4180	1%	8%	9%	48%	33%	
Colombia	842	2%	20%	28%	21%	8%	20%
Cote d'Ivoire	3				100%		
Cuba	301	2%	18%	20%	43%	17%	
Ecuador	40			15%	55%	25%	5%
Egypt	513	40%	4%	2%	6%	1%	46%
Estonia	91	4%	25%	9%	42%	10%	10%
Ethiopia	21		10%	33%	57%		
France	1716	2%	14%	10%	40%	34%	
Georgia	31	3%	19%	10%	39%	29%	
Ghana	6	50%	33%		17%		
Greece	1063	1%	17%	8%	42%	32%	
Hungary	1423	1%	8%	7%	45%	41%	
India	489	4%	15%	12%	37%	4%	27%
Iran	1348	3%	19%	10%	55%	13%	
Iraq	279	17%	29%	42%	10%	3%	
Ireland	1181	7%	16%	7%	47%	23%	
Kenya	42	14%	31%	24%	17%	5%	10%
Korea, Republic of	107	1%	13%	15%	56%	15%	
Mexico	256	1%	11%	12%	37%	9%	31%
Mongolia	10		10%	20%	60%	10%	
Montenegro	3		33%	33%	33%		
Morocco	7			29%	71%		
New Zealand	210	3%	8%	10%	37%	24%	19%
Nigeria	5		40%		60%		
Pakistan	138	7%	28%	51%	13%	1%	
Palestine	33	9%	27%	12%	48%	3%	
Panama	459	2%	24%	36%	31%	7%	
Paraguay	5	80%		20%			
Philippines	31		16%	6%	35%		42%
Poland	1477		11%	9%	53%	26%	1%
Portugal	48		2%	4%	40%	50%	4%
Qatar	35	29%	26%	37%	9%		
Saudi Arabia	172	16%	35%	26%	23%		
Senegal	4		50%	50%			
Serbia	267	1%	9%	6%	56%	27%	

Country	VWD	0-4	5-13	14-18	19-44	45+	Age Not Known
Slovak Republic	594		7%	6%	51%	35%	
Slovenia	180	1%	11%	8%	53%	28%	
South Africa	623		9%	5%	50%	32%	4%
Sudan	209	18%	41%	16%	19%	3%	3%
Turkey	1119	7%	27%	18%	39%	9%	
Uganda	3		100%				
United Kingdom	10254	3%	11%	7%	42%	37%	
United States	11463	7%	31%	23%	27%	13%	
Uruguay	214		51%	1%	48%		
Uzbekistan	93	3%	16%	22%	48%	11%	
Venezuela	894	2%	16%	8%	40%	16%	17%
Vietnam	73		26%	7%	53%	8%	5%
Zimbabwe	1				100%		

HIV and HCV infection (People currently living with HIV or HCV. 46 countries reported HIV and HCV data.)

Please note: the number of people infected with HCV does not refer to the number of people with active HCV.

Country	Hemophilia HIV+	Hemophilia HCV+	VWD HIV+	VWD HCV+
Afghanistan	0	4	No data	No data
Albania	0	70	No data	No data
Algeria	2	27	No data	No data
Argentina	60	615	0	21
Austria	144	205	No data	No data
Azerbaijan	No data	223	No data	52
Bangladesh	No data	1	No data	No data
Cameroon	0	5	No data	No data
Colombia	4	270	0	20
Costa Rica	13	50	No data	No data
Cote d'Ivoire	1	1	0	0
Cuba	4	143	0	12
Dominican Republic	0	20	0	0
Estonia	0	28	No data	1
Ethiopia	No data	No data	4	2
France	452	1730	14	157
Georgia	0	144	0	6
Germany	380	2000	No data	No data
Greece	59	335	1	25
Hungary	12	388	0	108
India	154	No data	No data	No data
Iran	26	319	No data	No data
Iraq	0	300	0	62
Ireland	32	140	0	11
Japan	725	1731	7	103
Jordan	2	46	No data	No data
Kenya	23	No data	No data	No data



Country	Hemophilia HIV+	Hemophilia HCV+	VWD HIV+	VWD HCV+
Korea, Republic of	18	149	0	0
Mauritius	0	6	No data	No data
Mexico	34	187	1	3
Morocco	No data	15	No data	No data
New Zealand	6	39	0	2
Norway	5	No data	0	No data
Pakistan	7	134	1	24
Saudi Arabia	31	88	No data	No data
Serbia	8	126	2	12
Slovak Republic	0	139	0	23
Slovenia	7	88	0	6
South Africa	69	217	2	3
Sudan	2	40	No data	No data
Thailand	10	60	No data	No data
United Kingdom	295	745	4	76
United States	1149	3720	28	221
Uzbekistan	2	272	No data	14
Venezuela	86	320	86	24
Vietnam	2	270	0	9
Total	3824	15410	150	997

Percentage of patients on prophylaxis (60 countries reported prophylaxis data.)

For all patients (Hemophilia A and B) that would be eligible for prophylactic treatment based on the protocols in their country.

Country	Percent under 18 on prophylaxis	Precise or estimate	Percent over 18 on prophylaxis	Precise or estimate
Albania	0%	Precise	0%	Precise
Algeria	60%	Estimate	25%	Estimate
Argentina	68%	Precise	4%	Precise
Australia	82%	Precise	53%	Precise
Austria	88%	Precise	63%	Precise
Azerbaijan	6%	Estimate	10%	Estimate
Bahrain	100%	Precise	50%	Precise
Belarus	80%	Estimate	0%	Estimate
Belgium	90%	Estimate	Not known	
Brazil	17%	Estimate	59%	Estimate
Colombia	90%	Estimate	50%	Estimate
Costa Rica	24%	Precise	0%	Precise
Cote d'Ivoire	0%	Precise	0%	Precise
Cuba	4%	Precise	2%	Precise
Ecuador	0%	Precise	2%	Precise
Eritrea	0%	Precise	0%	Precise
Estonia	100%	Precise	18%	Precise
Ethiopia	0%	Precise	0%	Precise
Finland	95%	Estimate	Not known	
France	80%	Estimate	40%	Estimate
Germany	100%	Estimate	55%	Estimate
Ghana	0%	Precise	0%	Precise
Greece	85%	Precise	23%	Estimate
Honduras	0%	Precise	0%	Precise
Hungary	90%	Estimate	55%	Estimate
India	1%	Estimate	0%	Estimate
Iran	20%	Estimate	0%	Precise
Iraq	100%	Estimate	10%	Estimate
Ireland	88%	Precise	75%	Precise
Japan	90%	Estimate	64%	Estimate

Country	Percent under 18 on prophylaxis	Precise or estimate	Percent over 18 on prophylaxis	Precise or estimate
Jordan	35%	Estimate	Not known	
Kenya	15%	Estimate	15%	Estimate
Latvia	99%	Estimate	56%	Estimate
Lithuania	100%	Precise	25%	Estimate
Mauritius	90%	Estimate	5%	Estimate
Montenegro	90%	Precise	0%	Precise
Morocco	30%	Estimate	10%	Estimate
New Zealand	67%	Estimate	32%	Estimate
Nigeria	0%	Precise	0%	Precise
Norway	100%	Estimate	80%	Estimate
Pakistan	10%	Estimate	1%	Precise
Philippines	1%	Estimate	1%	Estimate
Poland	99%	Estimate	20%	Estimate
Qatar	60%	Precise	45%	Precise
Romania	90%	Estimate	0%	Estimate
Senegal	67%	Estimate	28%	Estimate
Serbia	60%	Estimate	20%	Estimate
Slovak Republic	94%	Precise	40%	Precise
Slovenia	89%	Precise	86%	Precise
Sudan	0%	Estimate	0%	Estimate
Thailand	10%	Estimate	Not known	
Togo	10%	Estimate	Not known	
Tunisia	45%	Precise	Not known	
United Kingdom	95%	Estimate	70%	Estimate
United States	85%	Estimate	63%	Estimate
Uruguay	24%	Precise	6%	Estimate
Uzbekistan	0%	Precise	0%	Precise
Venezuela	40%	Precise	20%	Precise
Vietnam	0%	Estimate	0%	Estimate
Zimbabwe	0%	Precise	0%	Precise



Reported Use of Factor Concentrates in 2014: Factor VIII (77 countries reported Factor VIII data.)

The quantities of factor VIII in this chart are as reported to the WFH and are not independently verified. In some cases the numbers reported may be for one region or hospital only. Some countries report the amount of factor concentrate *consumed* in the year 2014 while others report the amount *purchased*. The per capita number divides the total IUs used by the total population of the country. This gives an indication of the amount of product being used in a country but cannot be used to determine the level of care for individual patients. Please note that some FVIII products are used in the treatment of von Willebrand disease and not for hemophilia A. Quantities reported were not independently verified except when the WFH has data on humanitarian donations it provided in 2014.

Country	Factor VIII total IU	Factor VIII plasma-derived	Factor VIII recombinant	Factor VIII humanitarian aid	Factor VIII per capita	FVIII per cap. without hum. aid	Total percent plasma-derived	Total percent recombinant
Afghanistan	300,000	No data	No data	300,000	0.009	0		
Albania	1,400,000	No data	No data	140,000	0.464	0.417		
Algeria	56,450,750	36,177,500	20,273,250	0	1.454	1.454	64	36
Argentina	152,300,000	110,150,000	42,150,000	350,000	3.54	3.532	72	28
Australia	156,240,000	18,960,250	137,279,750	0	6.942	6.942	12	88
Azerbaijan	18,000,000	18,000,000	No data	No data	1.858		100	
Bahrain	330,000	0	330,000	0	0.251	0.251	0	100
Bangladesh	670,325	670,325	No data	482,200	0.004	0.001	100	
Bolivia	375,000	375,000	0	375,000	0.035	0	100	0
Brazil	574,812,500	285,150,250	289,662,250	0	2.836	2.836	50	50
Cambodia	No data	No data	No data	375,520				
Cameroon	284,560	0	284,560	240,060	0.012	0.002	0	100
Canada	259,233,630	54,732,710	204,500,920	0	7.442	7.442	21	79
Colombia	227,082,000	122,801,000	104,281,000	90,000	4.91	4.908	54	46
Costa Rica	No data	No data	No data	0				
Cote d'Ivoire	331,504	No data	No data	331,504	0.015	0		
Cuba	3,636,500	3,636,500	0	514,285	0.329	0.283	100	0
Dominican Rep.	2,057,834	2,043,704	14,130	250,000	0.199	0.175	99	1
Ecuador	3,322,250	3,322,250	0	0	0.212	0.212	100	0
Egypt	28,000,000	28,000,000	No data	201,000	0.322	0.32	100	
Eritrea	40,000	No data	40,000	0	0.006	0.006		100
Estonia	4,070,500	4,001,500	69,000	0	3.236	3.236	98	2
Ethiopia	158,000	No data	158,000	158,000	0.002	0		100
Finland	42,690,750	4,702,500	37,988,250	No data	8.103		11	89
France	469,754,500	159,000,500	310,754,000	No data	7.09		34	66
Georgia	6,500,000	6,500,000	No data	No data	1.317		100	
Germany	487,078,542	199,655,112	287,423,430	0	6.014	6.014	41	59
Ghana	251,072	31,818	219,254	251,072	0.01	0	13	87
Greece	40,097,100	4,678,600	35,418,500	0	3.721	3.721	12	88
Honduras	622,000	No data	No data	622,000	0.072	0		
Hungary	83,500,000	47,500,000	36,000,000	0	8.418	8.418	57	43
India	4,901,353	4,781,353	120,000	2,007,540	0.004	0.002	98	2
Iran	175,000,000	175,000,000	0	2,841	2.165	2.165	100	0
Iraq	60,000,000	0	60,000,000	0	1.841	1.841	0	100
Ireland	39,584,250	1,688,000	37,896,250	0	8.191	8.191	4	96



Country	Factor VIII total IU	Factor VIII plasma- derived	Factor VIII recombinant	Factor VIII humanitarian aid	Factor VIII per capita	FVIII per cap. without hum. aid	Total percent plasma- derived	Total percent recombinant
Japan	595,500,000	82,000,000	513,500,000	0	4.685	4.685	14	86
Jordan	No data	No data	No data	401,932				
Kenya	800,000	750,000	50,000	800,000	0.018	0	94	6
Korea, Rep. of	162,308,000	40,356,000	121,952,000	0	3.31	3.31	25	75
Latvia	4,207,750	3,000,250	1,207,500	0	1.943	1.943	71	29
Lithuania	13,110,750	7,457,500	5,653,250	No data	3.74		57	43
Maldives	No data	No data	No data	151,800				
Mauritius	1,510,000	1,510,000	0	0	1.134	1.134	100	0
Mexico	146,138,850	123,769,850	22,369,000	472,500	1.215	1.211	85	15
Mongolia	918,300	No data	No data	222,000	0.311	0.236		
Montenegro	956,250	956,250	0	13,000	1.471	1.451	100	0
Morocco	5,133,833	3,961,833	1,172,000	2,836,640	0.156	0.07	77	23
New Zealand	26,085,250	3,938,250	22,147,000	0	5.926	5.926	15	85
Nigeria	1,150,995	463,859	687,136	540,995	0.006	0.003	40	60
Norway	27,900,000	No data	No data	0	5.42	5.42		
Pakistan	1,430,550	357,638	1,072,912	260,000	0.007	0.006	25	75
Palestine	4,224,000	No data	No data	508,600	2.326	2.045		
Panama	2,910,475	2,831,975	78,500	99,250	0.807	0.779	97	3
Paraguay	No data	No data	No data	452,000				
Philippines	1,485,389	1,160,965	324,424	899,389	0.014	0.005	78	22
Poland	193,218,450	189,197,750	4,020,700	No data	5.039		98	2
Portugal	43,761,500	17,928,500	25,833,000	No data	4.047		41	59
Qatar	1,095,000	No data	No data	No data	0.516			
Romania	22,082,950	16,962,700	5,120,250	30,000	1.016	1.015	77	23
Saudi Arabia	92,575,000	36,225,000	56,350,000	0	3.385	3.385	39	61
Senegal	444,600	30,000	414,600	444,600	0.033	0	7	93
Serbia	14,339,000	13,869,000	470,000	0	1.989	1.989	97	3
Slovak Republic	34,298,000	32,394,750	1,903,250	0	6.301	6.301	94	6
Slovenia	17,107,250	4,980,500	12,126,750	0	8.604	8.604	29	71
South Africa	51,819,800	50,716,300	1,103,500	0	1.071	1.071	98	2
Sudan	4,043,440	4,024,500	18,940	542,940	0.114	0.099	100	0
Thailand	687,500	No data	No data	687,500	0.01	0		
Togo	90,834	No data	No data	90,834	0.012	0		
Tunisia	11,345,500	7,054,000	4,291,500	0	1.037	1.037	62	38
Turkey	254,873,250	172,795,000	82,078,250	No data	3.123		68	32
Uganda	174,350	174,350	0	174,350	0.005	0	100	0
United Kingdom	523,964,867	50,275,980	473,688,887	0	8.22	8.22	10	90
Uruguay	5,202,500	5,004,500	198,000	0	1.561	1.561	96	4
Uzbekistan	464,000	464,000	No data	464,000	0.016	0	100	
Venezuela	57,512,000	14,512,000	43,000,000	15,000	1.992	1.992	25	75
Vietnam	9,288,270	9,288,270	0	500,000	0.099	0.094	100	0
Zimbabwe	563,750	563,750	0	563,750	0.041	0	100	0
Total	5,233,797,123	2,190,534,092	3,005,693,893	17,862,102			42%	57%



Reported Use of Factor Concentrates in 2014: Factor IX (71 countries reported Factor IX data.)

The quantities of factor IX in the chart above are as reported to the WFH and are not independently verified. In some cases the numbers reported may be for one region or hospital only. Some countries report the amount of factor concentrate *consumed* in the year 2014 while others report the amount *purchased*. The factor IX per capita divides the total IUs used by the total population of the country. This gives an indication of the amount of product being used in a country but cannot be used to determine the level of care for individual patients. Quantities reported were not independently verified except when the WFH has data on humanitarian donations it provided in 2014.

Country	Factor IX total IU	Factor IX plasma-derived	Factor IX recombinant	Factor IX humanitarian aid	Factor IX per capita	Factor IX per capita without humanitarian aid	Total percent plasma-derived	Total percent recombinant
Afghanistan	25,000	No data	No data	25,000	0.001	0.000		
Albania	700,000	No data	No data	81,900	0.232	0.205		
Algeria	7,254,600	7,254,600	No data	No data	0.187		100	
Argentina	15,150,000	10,700,000	4,450,000	6,000	0.352	0.352	71	29
Australia	30,794,000	3,866,500	26,927,500	0	1.368	1.368	13	87
Azerbaijan	2,000,000	2,000,000	No data	No data	0.206		100	
Bahrain	130,000	130,000	0	0	0.099	0.099	100	0
Bangladesh	78,750	No data	78,750	78,750	0.000	0.000		100
Bolivia	31,500	31,500	No data	31,500	0.003	0.000	100	
Brazil	96,563,750	96,563,750	0	0	0.476	0.476	100	0
Cambodia	No data	No data	No data	29,580				
Cameroon	31,500	0	31,500	31,500	0.001	0.000	0	100
Canada	52,068,501	4,084,387	47,984,114	0	1.495	1.495	8	92
Colombia	24,855,000	15,075,000	9,780,000	122,000	0.537	0.535	61	39
Costa Rica	No data	No data	No data	0				
Cote d'Ivoire	11,466	0	11,466	11,466	0.001	0.000	0	100
Cuba	445,000	445,000	0	0	0.040	0.040	100	0
Dominican Rep.	300,000	300,000	0	157,500	0.029	0.014	100	0
Ecuador	138,800	138,800	0	0	0.009	0.009	100	0
Egypt	No data	No data	No data	223,620				
Eritrea	6,000	No data	No data	No data	0.001			
Estonia	293,900	No data	No data	No data	0.234			
Ethiopia	63,000	No data	63,000	63,000	0.001	0.000		100
Finland	7,812,000	605,000	7,207,000	No data	1.483		8	92
France	72,973,000	27,023,750	45,949,250	No data	1.101		37	63
Georgia	842,000	842,000	No data	No data	0.171		100	
Germany	55,999,815	36,476,200	19,523,615	0	0.691	0.691	65	35
Ghana	8,450	0	8,450	8,450	0.000	0.000	0	100
Greece	5,224,800	481,800	4,743,000	0	0.485	0.485	9	91
Honduras	No data	No data	No data	31,500				
Hungary	6,500,000	6,500,000	0	No data	0.655		100	0
India	1,226,400	1,226,400	0	0	0.001	0.001	100	0
Iran	17,500,000	17,500,000	0	0	0.216	0.216	100	0
Iraq	15,000,000	No data	15,000,000	0	0.460	0.460		100
Ireland	11,305,500	0	11,305,500	0	2.339	2.339	0	100
Japan	105,200,000	48,400,000	56,800,000	0	0.828	0.828	46	54



Country	Factor IX total IU	Factor IX plasma-derived	Factor IX recombinant	Factor IX humanitarian aid	Factor IX per capita	Factor IX per capita without humanitarian aid	Total percent plasma-derived	Total percent recombinant
Jordan	No data	No data	No data	146,050				
Kenya	80,000	No data	80,000	80,000	0.002	0.000		100
Korea, Rep. of	37,203,000	2,775,000	34,428,000	0	0.759	0.759	7	93
Latvia	617,000	617,000	0	0	0.285	0.285	100	0
Lithuania	2,486,800	2,486,800	0	No data	0.709		100	0
Mauritius	127,500	127,500	0	No data	0.096		100	0
Mexico	19,803,121	19,504,121	299,000	109,521	0.165	0.164	98	2
Mongolia	270,600	No data	No data	No data	0.092			
Montenegro	102,000	102,000	0	0	0.157	0.157	100	0
Morocco	181,000	85,240	95,760	63,000	0.005	0.004	47	53
New Zealand	3,609,000	1,073,000	2,536,000	0	0.820	0.820	30	70
Nigeria	284,000	0	284,000	0	0.002	0.002	0	100
Norway	No data	No data	No data	0				
Pakistan	533,000	26,650	506,350	No data	0.003		5	95
Palestine	960,000	No data	No data	No data	0.529			
Panama	46,200	46,200	0	No data	0.013		100	0
Philippines	329,611	30,410	299,201	314,611	0.003	0.000	9	91
Poland	26,057,800	25,199,050	858,750	No data	0.680		97	3
Portugal	5,822,000	3,782,000	2,040,000	No data	0.538		65	35
Qatar	255,000	No data	No data	No data	0.120			
Romania	2,294,500	2,294,500	0	No data	0.106		100	0
Saudi Arabia	12,000,000	7,000,000	5,000,000	0	0.439	0.439	58	42
Senegal	26,000	0	26,000	26,000	0.002	0.000	0	100
Serbia	1,480,000	1,480,000	0	0	0.205	0.205	100	0
Slovak Republic	2,233,100	2,233,100	0	0	0.410	0.410	100	0
Slovenia	916,500	706,500	210,000	0	0.461	0.461	77	23
South Africa	7,918,000	7,918,000	0	0	0.164	0.164	100	0
Sudan	849,000	No data	No data	63,000	0.024	0.022		
Tunisia	1,324,750	1,324,750	0	0	0.121	0.121	100	0
Turkey	4,339,800	4,339,800	No data	No data	0.053		100	
United Kingdom	88,250,776	11,157,630	77,093,146	0	1.384	1.384	13	87
Uruguay	540,000	No data	0	0	0.162	0.162		0
Venezuela	8,708,100	8,708,100	No data	289,900	0.302	0.292	100	
Vietnam	1,236,500	1,236,500	0	0	0.013	0.013	100	0
Zimbabwe	63,000	0	63,000	63,000	0.005	0.000	0	100
Total	761,480,390	383,898,538	373,682,352	2,056,848			50%	49%



Annual Global Survey 2014 questionnaire

A. National Hemophilia Organization

Organization name	
City	
Country	
Phone	
E-mail	
This form completed by:	First name Last name Email

The WFH would like to know how you collect the data you are providing for this survey. If you have a registry, we would like to know more about the registry. A registry is a regularly updated centralized list of identified people with hemophilia (PWH) or inherited bleeding disorders. A registry includes information on personal details, diagnosis, treatment, and complications.

What is the source of the numbers provided for this survey?	Check one ☐ Hemophilia Society and/or NMO registry or database ☐ Hospital(s)/HTC(s) registry or database ☐ Health Ministry registry or database ☐ Other (please describe):
How often is your database updated?	☐ Ongoing update (can be updated anytime) ☐ Yearly update (the registry is updated once each year) ☐ Other (please describe):
Who updates the database?	☐ Doctors update the database ☐ Patient organization updates the database ☐ Hospitals or clinics update the database ☐ Other (please describe):

B. Identified patients

(Please DO NOT estimate or guess)	Number	Not known
1. Total number of identified people with hemophilia A or B, or type unknown (PWH)		☐
2. Number of identified people with von Willebrand disease (VWD)		☐
3. Number of identified people with other hereditary bleeding disorders (including rare factor deficiencies and inherited platelet disorders. See question 6 for the list of specific disorders.)		☐
Do you consider these numbers to be accurate?	Yes ☐	Not sure ☐



4. Number of people with Hemophilia and von Willebrand disease by age group

Age group	Number with hemophilia A	Number with hemophilia B	Number with hemophilia type unknown	Number with VWD
0 - 4 years old				
5 - 13 years old				
14 - 18 years old				
19 - 44 years old				
45 years or older				
Patients with age Unknown				
No age data	☐	☐	☐	☐

The age distribution of Hemophilia A, B and unknown should be equal to the number of PWH in question B1

The age distribution of vWD should be equal to the number of vWD in question B2

Do you consider these numbers to be accurate?	Yes ☐	Not sure ☐
5. Do you collect age data in a format that does not match question 4? (If you do collect age data in another format, please send it to the WFH in a separate attachment.)	Yes ☐	

6. Type of hereditary bleeding disorder

The sum of *Male*, *Female*, and *Gender Unknown* should be equal to *Total*.

Diagnosis	Total	Male	Female	Gender unknown	No data
Hemophilia A					☐
Hemophilia B					☐
Hemophilia, type unknown					☐
von Willebrand disease					☐
Factor I deficiency					☐
Factor II deficiency					☐
Factor V deficiency					☐
Factor V+VIII deficiency					☐
Factor VII deficiency					☐
Factor X deficiency					☐
Factor XI deficiency					☐
Factor XIII deficiency					☐
Rare factor deficiency: type unknown					☐
Platelet disorders: Glanzmann's thrombasthenia					☐
Platelet disorders: Bernard Soulier Syndrome					☐
Platelet disorders: other or unknown					☐

The sum of Totals Hemophilia A, B, and type unknown should be equal to the number of PWH in question B1.

The Total of vWD should be equal to the number of vWD in question B2

The sum of Total of the all other bleeding and platelets disorders should be equal to the number of OBD in question B3

Do you consider these numbers to be accurate?	Yes ☐	Not sure ☐
---	------------------------------	-----------------------------------



7. How are patients with rare bleeding disorders (deficiency in FI, FII, FV, FV+VIII, FVII, FX, FXI FXIII) classified?

Factor level measurements ☐	Clinical diagnosis ☐ (bleeding, family history)	Other ☐ (please describe):	No data ☐
--	---	--	----------------------------------

How are patients with von Willebrand Disease classified?

Factor level measurements ☐	Severe bleeding symptoms ☐	Other ☐ (please describe):	No data ☐
--	---	--	----------------------------------

8. Number of identified people with hemophilia by diagnosis of severity

There are three levels of **severity** of hemophilia: **mild**, **moderate**, and **severe**. The severity of hemophilia depends on the amount of clotting factor in the person's blood.

A person (male or female) with 5-40 per cent of the normal amount of clotting factor has **mild** hemophilia.

A person (male or female) with between 1-5 per cent of the normal amount of clotting factor has **moderate** hemophilia.

A person (male or female) with less than 1 per cent of the normal amount of clotting factor has **severe** hemophilia.

A woman who has less than 40 per cent of the normal level of clotting factor is no different from a man with the same factor levels—she has hemophilia.

Type of hemophilia	Mild (factor level above 5%)	Moderate (factor level 1% to 5%)	Severe (factor level below 1%)	Severity unknown	No Data
Hemophilia A male					☐
Hemophilia A female					☐
Hemophilia B male					☐
Hemophilia B female					☐

The sum of Hemophilia A Male mild, moderate, severe and unknown should be equal to number of Hemophilia A Male in question 6

The sum of Hemophilia A Female mild, moderate, severe and unknown should be equal to number of Hemophilia A female in question 6

The sum of Hemophilia B Male mild, moderate, severe and unknown should be equal to number of Hemophilia B Male in question 6

The sum of Hemophilia B Female mild, moderate, severe and unknown should be equal to number of Hemophilia B female in question 6

Do you consider these numbers to be accurate?	Yes ☐	Not sure ☐
---	------------------------------	-----------------------------------

9. Number of severe VWD patients

Total number of severe (type 3) VWD patients	Number of VWD patients receiving replacement therapy	Number of VWD patients with severe bleeding symptoms	No Data
			☐

Do you consider these numbers to be accurate?	Yes ☐	Not sure ☐
---	------------------------------	-----------------------------------

10. INHIBITORS: Number of identified people with hemophilia with current clinically significant inhibitors. (Patients who do not respond to normal treatment.)

Type of hemophilia	Total number with active inhibitors	New cases of inhibitors in 2014	No Data
Hemophilia A			☐
Hemophilia B			☐



11. Products used to treat hemophilia: How many patients were treated with the following products? (Please note: we are asking for a number, not a percentage.)

Treatment product	Number treated	Product is available	Product is used	Product is not used
Plasma		☐	☐	☐
Cryoprecipitate		☐	☐	☐
Plasma-derived concentrate		☐	☐	☐
Recombinant concentrate		☐	☐	☐
DDAVP (Desmopressin)		☐	☐	☐

12. Products used to treat VWD: How many patients were treated with the following products? (Please note: we are asking for a number, not a percentage.)

Treatment product	Number treated	Product is available	Product is used	Product is not used
Plasma		☐	☐	☐
Cryoprecipitate		☐	☐	☐
Plasma-derived concentrate		☐	☐	☐
DDAVP (Desmopressin)		☐	☐	☐

13. HIV and hepatitis C infection among living people with hemophilia (Please note: we are asking for a number, not a percentage.)

Infectious Disease	Number of people infected	Number of people tested	No Data
HIV			☐
Hepatitis C			☐

14. HIV and hepatitis C infection among living people with von Willebrand disease (Please note: we are asking for a number, not a percentage.)

Infectious Disease	Number of people infected	Number of people tested	No Data
HIV			☐
Hepatitis C			☐

15. Number and cause of deaths of people with bleeding disorders (January 1-December 31, 2014)

Cause of death	Number of people with Hemophilia A & B	Number of people with von Willebrand disease	Number of people with other inherited bleeding disorders
Bleeding			
HIV			
Liver disease			
Other causes			



C. Hemophilia Care System in Your Country

A Hemophilia Treatment Centre (HTC) is a medical centre providing basic diagnosis and treatment for inherited bleeding disorders.

A Hemophilia Comprehensive Care Centre (HCCC) is a medical centre providing a full range of facilities for the diagnosis and management of inherited bleeding disorders.

16. How many hemophilia treatment centres are there in your country?	
Of these, how many are hemophilia comprehensive care centres ?	
Percentage of hemophilia patients with access to hemophilia treatment centres:	

Prophylaxis is regular, long-term treatment with clotting factor concentrates to prevent bleeds. Please indicate if the percentage provided is precise or an estimate.

17. What percentage of eligible children (under age 18) with severe hemophilia are on prophylaxis?		Precise: ☐ Estimate: ☐	Not known ☐
What percentage of eligible adults (over age 18) with severe hemophilia are on prophylaxis?		Precise: ☐ Estimate: ☐	Not known ☐

D. The Cost and Use of Factor Concentrates

18. Annual usage of factor concentrates	Factor VIII	Not known	Factor IX	Not known
IN TOTAL how many international units (IU) of factor concentrates were used in your country in 2014?		☐		☐
How many international units of plasma-derived concentrates were used in your country in 2014?		☐		☐
How many international units of recombinant concentrates were used in your country in 2014?		☐		☐

The sum of Total of FVIII should be equal to sum of FVIII plasma-derived and FVIII recombinant
The sum of Total of FIX should be equal to sum of FIX plasma-derived and FIX recombinant

Of the number reported above how many international units were humanitarian aid ?		☐		☐
--	--	--------------------------	--	--------------------------

Do you consider these numbers to be accurate?	Yes ☐	Not sure ☐
---	------------------------------	-----------------------------------

PLEASE NOTE: If a product used in your country is not listed, please add it at the bottom of the appropriate table.

Currency:	Tax included? No ☐ Yes ☐	Tax rate:
-----------	--	-----------



19. Factor VIII Concentrates used in 2014

(Please check the box on the left if a product is used, and if known, fill out the cost per international unit in the currency used to purchase the product. Please indicate if this price includes tax.)

Used	Brand Name	Manufacturer	Price per IU
☐	Aafact	Sanquin	
☐	Advate rAHF PFM	Baxter Bioscience	
☐	Aleviate	CSL Behring	
☐	Alphanate	Grifols	
☐	Amofil	Sanquin OY	
☐	Beriate P	CSL Behring	
☐	BIOSTATE	CSL Bioplasma	
☐	Conco-eight-HT	Benesis	
☐	Confact F	Kaketsuken	
☐	Cross Eight M	Japanese Red Cross	
☐	Elocta/Eloctate	Biogen Idec	
☐	Emoclot D.I.	Kedrion	
☐	FACTANE	LFB	
☐	Factor 8 Y	BioProducts Lab.	
☐	Faktor VIII SDH Intersero	Intersero	
☐	Fanhdi	Grifols	
☐	GreenEight	GreenCross	
☐	GreenGene	GreenCross	
☐	GreenMono	Greencross Corp	
☐	Haemate P (= Haemate HS)	CSL Behring	
☐	Haemoctin SDH	Biotest	
☐	Haemosolvate Factor VIII	National Bioproducts	
☐	Helixate NexGen = Helixate FS	CSL Behring	
☐	Hemofil M AHF	Baxter BioScience	
☐	HEMORAAS SD plus H	Shanghai RAAS	
☐	HEMORAAS-HP, SD plus H	Shanghai RAAS	
☐	HEMORAAS-IP, SD plus H	Shanghai RAAS	
☐	Humate P	CSL Behring	
☐	Humafaktor 8	Human BioPlazma	
☐	Human Coagulation Factor VIII	Baltijas Terapeitiskais Serviss	
☐	Immunate	Baxter BioScience	
☐	Koate DVI	Talecris	
☐	Kogenate FS = KOGENATE Bayer (in EU)	Bayer	
☐	Monoclate P	CSL Behring	
☐	Novoeight	NovoNordisk	
☐	Octanate	Octapharma	
☐	Octanativ-M	Octapharma	



☐	Octavi SD	Octapharma	
☐	Optivate	Bio Products Laboratory	
☐	Recombinate rAHF	Baxter BioScience	
☐	ReFacto AF	Pfizer (Wyeth)	
☐	Replenate	Bio Products Laboratory	
☐	Wilate	Octapharma	
☐	Xyntha	Pfizer (Wyeth)	
☐	Other:		

20. Factor IX Concentrates used in 2014

(Please check the box on the left if a product is used, and if known, fill out the cost per international unit in your currency.)

Used	Brand Name	Manufacturer	Price per IU
☐	Aimafix	Kedrion	
☐	AlphaNine SD	Grifols	
☐	Alprolix	Biogen Idec	
☐	BeneFIX	Wyeth	
☐	Berinin-P = Berinin HS	CSL Behring	
☐	BETAFACT	LFB	
☐	Christmassin-M	Benesis	
☐	Factor IX Grifols	Grifols	
☐	Faktor IX SDN	Biotest	
☐	Fixnove	Baxter	
☐	Hemo-B-RAAS	Shanghai RAAS	
☐	Haemonine	Biotest	
☐	Immunine	Baxter BioScience	
☐	MonoFIX-VF	CSL Bioplasma	
☐	Mononine	CSL Behring	
☐	Nanofix	Octapharma	
☐	Nanotiv	Octapharma	
☐	Nonafact	Sanquin	
☐	Novact M	Kaketsuken	
☐	Octafix	Octapharma	
☐	Octanine F	Octapharma	
☐	Replenine – VF	BioProducts Lab.	
☐	Other:		



21. Prothrombin Complex Concentrates used in 2014

(Please check the box on the left if a product is used, and if known, fill out the cost per international unit in your currency.)

Used	Brand Name	Manufacturer	Price per IU
☐	Bebulin VH	Baxter BioScience	
☐	Beriplex P/N	CSL Behring	
☐	Cofact	Sanquin	
☐	Facnyne	Greencross Corp	
☐	Haemosolvex Factor IX	National Bioproducts	
☐	HT DEFIX	SNBTS	
☐	Kanokad Confidex	LFB	
☐	KASKADIL	LFB	
☐	Octaplex	Octapharma	
☐	PPSB-HT	Nihon Pharmaceutical	
☐	PPSB-human SD/Nano 300/600	German Red Cross NSTOB	
☐	Profilnine SD	Grifols	
☐	Proplex – T	Baxter BioScience	
☐	Prothrombinex PXT	CSL Bioplasma	
☐	Prothrombinex- VF	CSL Bioplasma	
☐	Prothromplex-T	Baxter BioScience	
☐	Prothroras	Shanghai RAAS	
☐	UMAN Complex D.I.	Kedrion	
☐	Other:		

22. Other Products used in 2014

(Please check the box on the left if a product is used, and if known, fill out the cost per international unit in your currency.)

Used	Brand Name	Manufacturer	Price per IU
☐	Aryoseven	Aryogen	
☐	Clottafact Wilstart	LFB	
☐	Clottagen (fibrinogen)	LFB	
☐	Coagil 7 (activated factor VII)	Pharmstandard	Price per vial: Vial size:
☐	FACTEUR VII	LFB	
☐	Factor VII	Baxter BioScience	
☐	Factor VII	Bio Products	
☐	Factor X P Behring	CSL Behring	
☐	Factor XI	Bio Products	
☐	FEIBA	Baxter	
☐	Fibrinogen HT	Benesis	
☐	Fibrogammin P (=Fibrogammin HS) (Factor XIII)	CSL Behring	
☐	FIBRORAAS (fibrinogen)	Shanghai RAAS	
☐	Haemocomplettan P = Haemocomplettan HS (fibrinogen)	CSL Behring	



☐	HEMOLEVEN (Factor XI)	LFB	
☐	NovoSeven (=Niasase) (activated factor VII)	NovoNordisk	Price per vial: Vial size:
☐	Riastap	CSL Behring	
☐	Tretten rXIII	NovoNordisk	
☐	WILFACTIN (Von Willebrand Factor)	LFB	
☐	Other:		



Glossary

Bernard-Soulier syndrome: A severe congenital bleeding disorder characterized by thrombocytopenia and large platelets, due to a defect in the platelet glycoprotein 1b/V/IX receptor.

Cryoprecipitate: A fraction of human blood prepared from fresh plasma. Cryoprecipitate is rich in factor VIII, von Willebrand factor, and fibrinogen (factor I). It does not contain factor IX.

Desmopressin (DDAVP): A synthetic hormone used to treat most mild cases of von Willebrand disease and mild hemophilia A. It is administered intravenously or by subcutaneous injection or by intranasal spray.

Factor concentrates: These are fractionated, freeze-dried preparations of individual clotting factors or groups of factors derived from donated blood.

Glanzmann's thrombasthenia: A severe congenital bleeding disorder in which the platelets lack glycoprotein IIb/IIIa, the blood platelet count is normal, but their function is very abnormal.

Hemophilia A: A condition resulting from factor VIII deficiency, also known as classical hemophilia.

Hemophilia B: A condition resulting from factor IX deficiency, also known as Christmas disease.

Hemophilia treatment centre: A specialized medical centre that provides diagnosis, treatment, and care for people with hemophilia and other inherited bleeding disorders.

HIV: Human immunodeficiency virus. The virus that causes AIDS.

Identified person: A living person known to have hemophilia, von Willebrand disease, or another bleeding disorder.

Inhibitors: A PWH has inhibitors when their body's immune system attacks the molecules in factor concentrate, rendering it ineffective.

International Unit (IU): A standardized measurement of the amount of factor VIII or IX contained in a vial. Usually marked on vials as 250 IU, 500 IU, 1000 IU or 2000 IU.

Mild hemophilia: Condition resulting from a level of factor VIII or factor IX clotting activity below normal but above 5% of normal activity in the bloodstream. (National definitions differ on the upper limit for mild hemophilia, ranging from 24% to 50%. The normal range of factor VIII or IX is 50 to 200%)

Moderate hemophilia: Condition resulting from a level of factor VIII or factor IX clotting activity between 1 to 5 % of normal activity in the bloodstream.

Plasma-derived products: Factor concentrates that contain factor VIII or IX that have been fractionated from human blood.

PWH: Person with hemophilia

Recombinant products: Factor concentrates that contain factor VIII or IX that have been artificially produced and are, therefore, not derived from human blood.

Registry: A database or record of identified people with hemophilia or inherited bleeding disorders. A registry includes information on personal details, diagnosis, treatment and complications.

Severe hemophilia: Condition resulting from a level of factor VIII or factor IX clotting activity of less than 1 % in the bloodstream.

von Willebrand disease (VWD): An inherited bleeding disorder resulting from a defect or deficiency of von Willebrand factor.





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