WORLD FEDERATION OF HEMOPHILIA
REPORT ON THE

ANNUAL GLOBAL SURVEY 2015

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

October 2016

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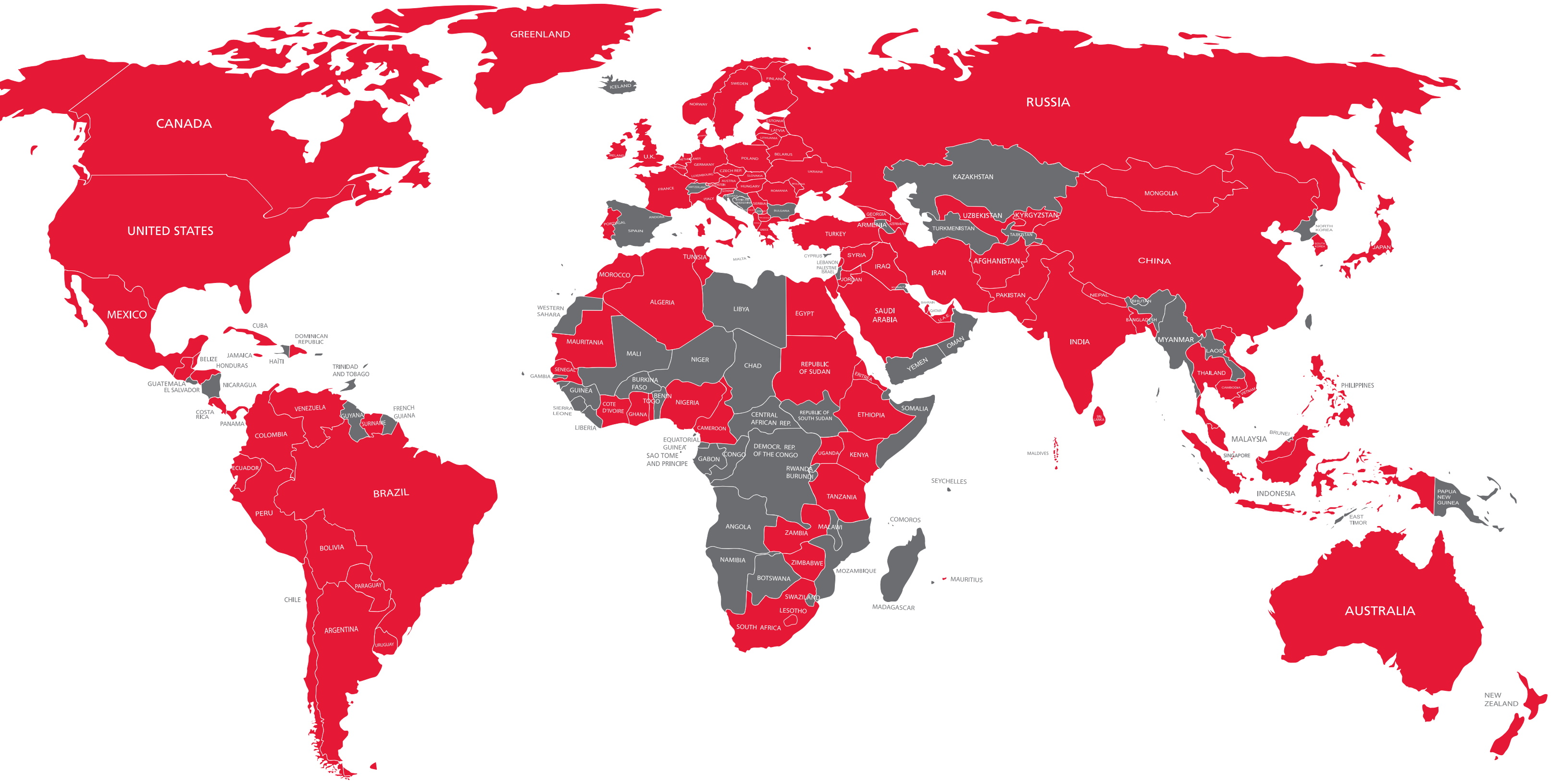
COUNTRIES INCLUDED IN THE REPORT ON THE ANNUAL GLOBAL SURVEY 2015



🟥 Countries included

⬛ Countries not included

The WFH has a total of 134 National Member Organizations (NMOs). The Report on the Annual Global Survey 2015 includes data from 111 NMOs.

INTRODUCTION TO THE REPORT ON THE ANNUAL GLOBAL SURVEY 2015

The Report on the Annual Global Survey 2015 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 2015 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 2015 survey is the seventeenth WFH survey. This report also uses data from the year 2014. Not all of our members are able to report every year. Previous Annual Global Survey reports have used historical data going back more than 1 year. A list of participating countries and the last year they provided data can be found on page 21. This report includes data on more than 304,000 people with hemophilia, von Willebrand disease and other bleeding disorders in 111 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.

Total population numbers are used in Table 6 Population statistics and in the calculation for factor VIII and IX per capita (Table 16 and 17). The source from 1999 to 2014 was The World Factbook, Central Intelligence Agency. As of 2015, this was changed to The World Bank Group. General population numbers are estimates based on national government data.

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 2015 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 2015. In some cases the numbers reported may be based on an estimate or from one region or hospital only. 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 do not 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.

KEY NUMBERS FROM THE 2015 REPORT ON THE ANNUAL GLOBAL SURVEY

111 **COUNTRIES REPRESENTED**

304,362

People with bleeding disorders identified

FROM 2014 TO 2015

5.6%

(17,296)

Increase in number of people with bleeding disorders identified

187,183 People with Hemophilia

74,819 People with von Willebrand disease (VWD)

42,360 People with Other Bleeding Disorders

Factor VIII Usage per capita

0.53 IU

(0.05 – 3.52)

Median (IQR)

(81 countries, 63% of world population)

WFH

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REPORT ON THE ANNUAL GLOBAL SURVEY **2015**
SUMMARY DEMOGRAPHICS

Table 1. Demographics

Number of countries in this survey	**111**
Percentage of world population covered by countries included in 2015 survey report	**91%**
Number of people identified with hemophilia	**187,183**
Number of people identified with von Willebrand disease	**74,819**
Number of people identified with other bleeding disorders	**42,360**
Total number of people identified with bleeding disorders	**304,362**
Number of people identified with hemophilia A	**151,159**
Number of people identified with hemophilia B	**30,310**
Number of people with hemophilia A with current clinically identified inhibitors	**3,099**
Number of people with hemophilia B with current clinically identified inhibitors	**154**

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.

Table 2. Factor VIII usage 2015

	FACTOR USAGE	NUMBER OF COUNTRIES
Mean global per capita factor VIII usage	**2.20 IU**	**81**
Median global per capita factor VIII usage	**0.53 IU**	**81**
Interquartile range (IQR) global per capita factor VIII usage	**3.47 IU (0.05 to 3.52)**	**81**
Total reported annual global consumption of factor VIII concentrates	**8,255,077,208 IU**	**81**

Table 3. Factor IX usage 2015

	FACTOR USAGE	NUMBER OF COUNTRIES
Mean global per capita factor IX usage	**0.41 IU**	**68**
Median global per capita factor IX usage	**0.18 IU**	**68**
Interquartile range (IQR) global per capita factor IX usage	**0.61 IU (0.01 to 0.61)**	**68**
Total reported annual global consumption of factor IX concentrates	**1,318,398,256 IU**	**68**

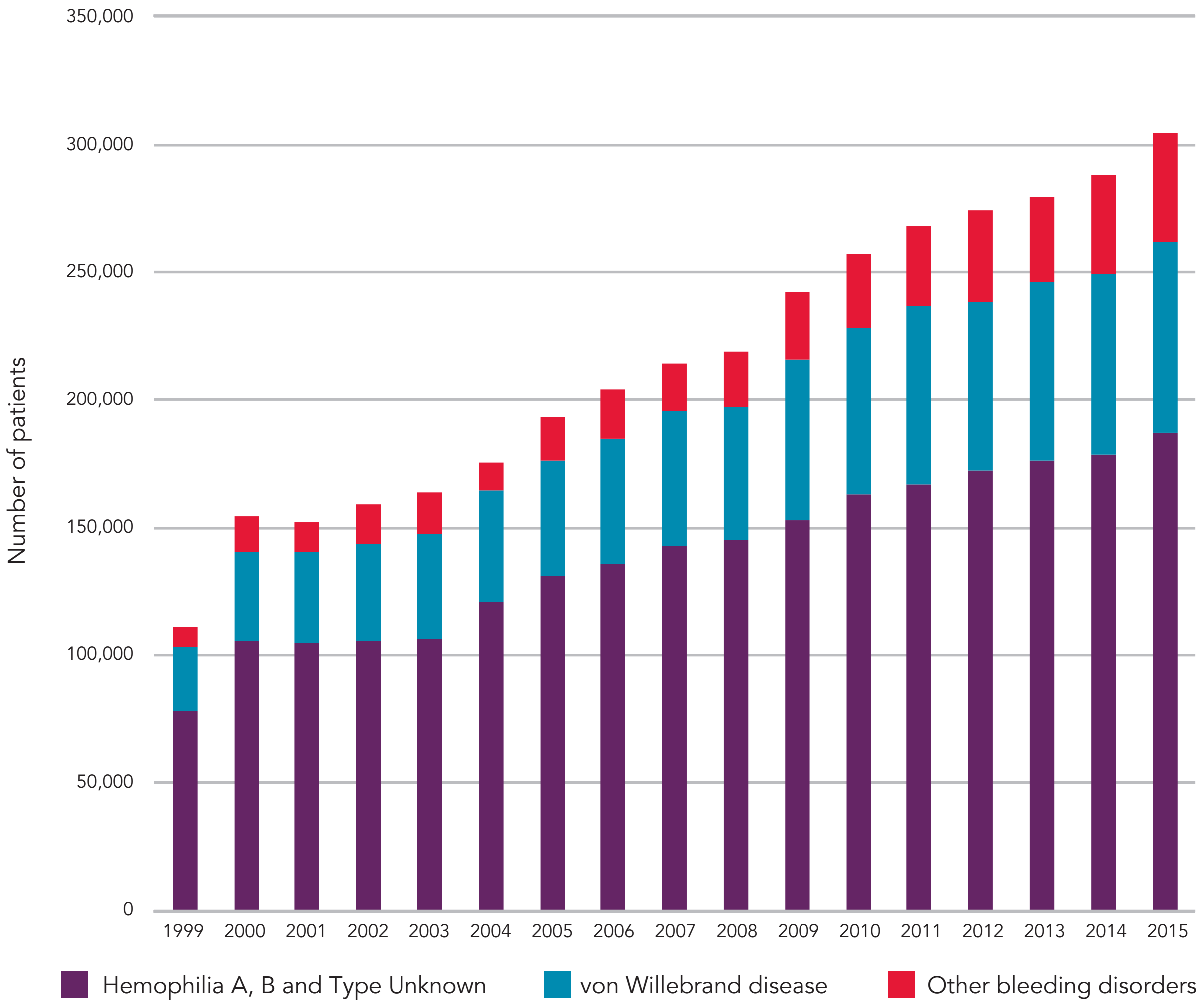
The average per capita and total consumption figures reported this year cannot be directly compared to the figures from other survey years as the group of countries reporting factor usage changes from year to year. To illustrate, if a large country using large amounts of factor or a large country using 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 2014 and 2015 surveys.

Table 4. Factor use in 2014 and 2015

	2014	2015	COUNTRIES REPORTING
Mean global per capita factor VIII usage	**2.11 IU**	**2.28 IU**	**54**
Median global per capita factor VIII usage	**1.23 IU**	**1.04 IU**	**54**
Interquartile range (IQR) global per capita factor VIII usage	**3.57 IU (0.02 to 3.59)**	**3.86 IU (0.05 to 3.91)**	**54**
Mean global per capita factor IX usage	**0.35 IU**	**0.38 IU**	**47**
Median global per capita factor IX usage	**0.21 IU**	**0.21 IU**	**47**
Interquartile range (IQR) global per capita factor IX usage	**0.53 IU (0.005 to 0.53)**	**0.65 IU (0.009 to 0.66)**	**47**

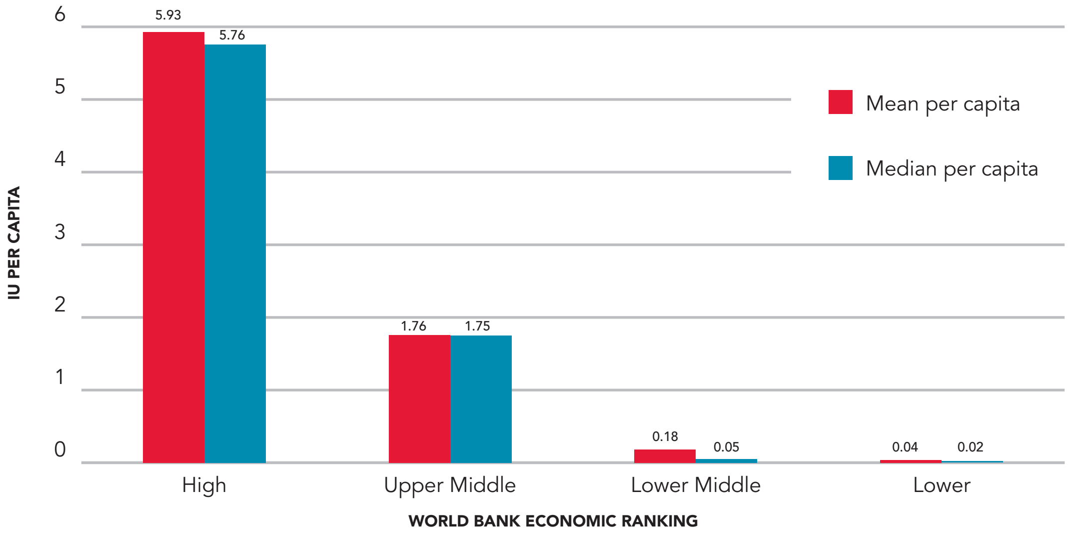
Figure A. Identified patients – all bleeding disorders



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.

Figure B1. Mean global factor VIII use per capita

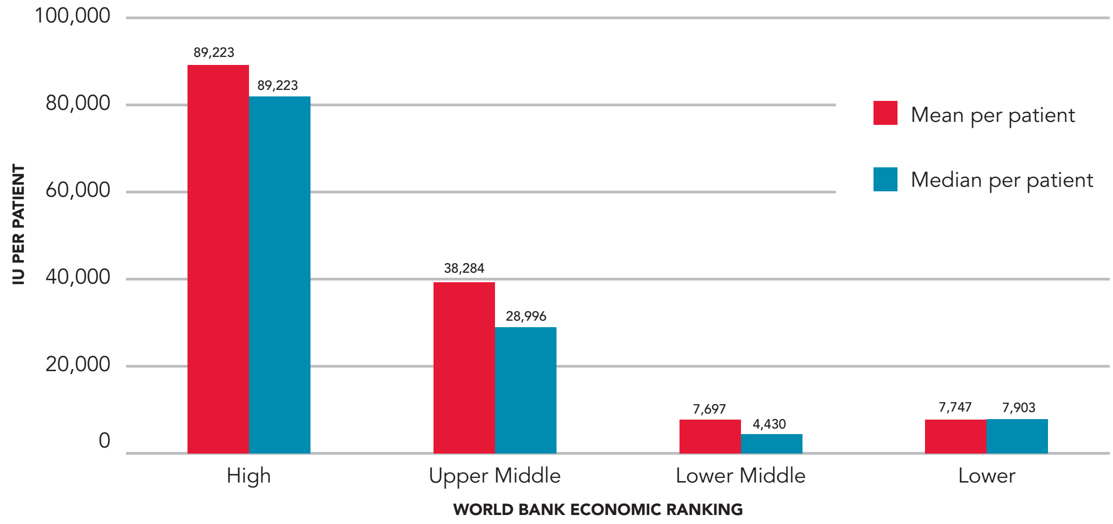
(Data from 79 countries.)



Economic category based on The World Bank Group 2015 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". (GNI in US dollars: D lower income, $0-$1,025; C lower middle income, $1,026 - $4,035; B upper middle income, $4,036 - $12,475; and A high income, $12,475 or more.)

Figure B2. Mean global factor VIII use per patient

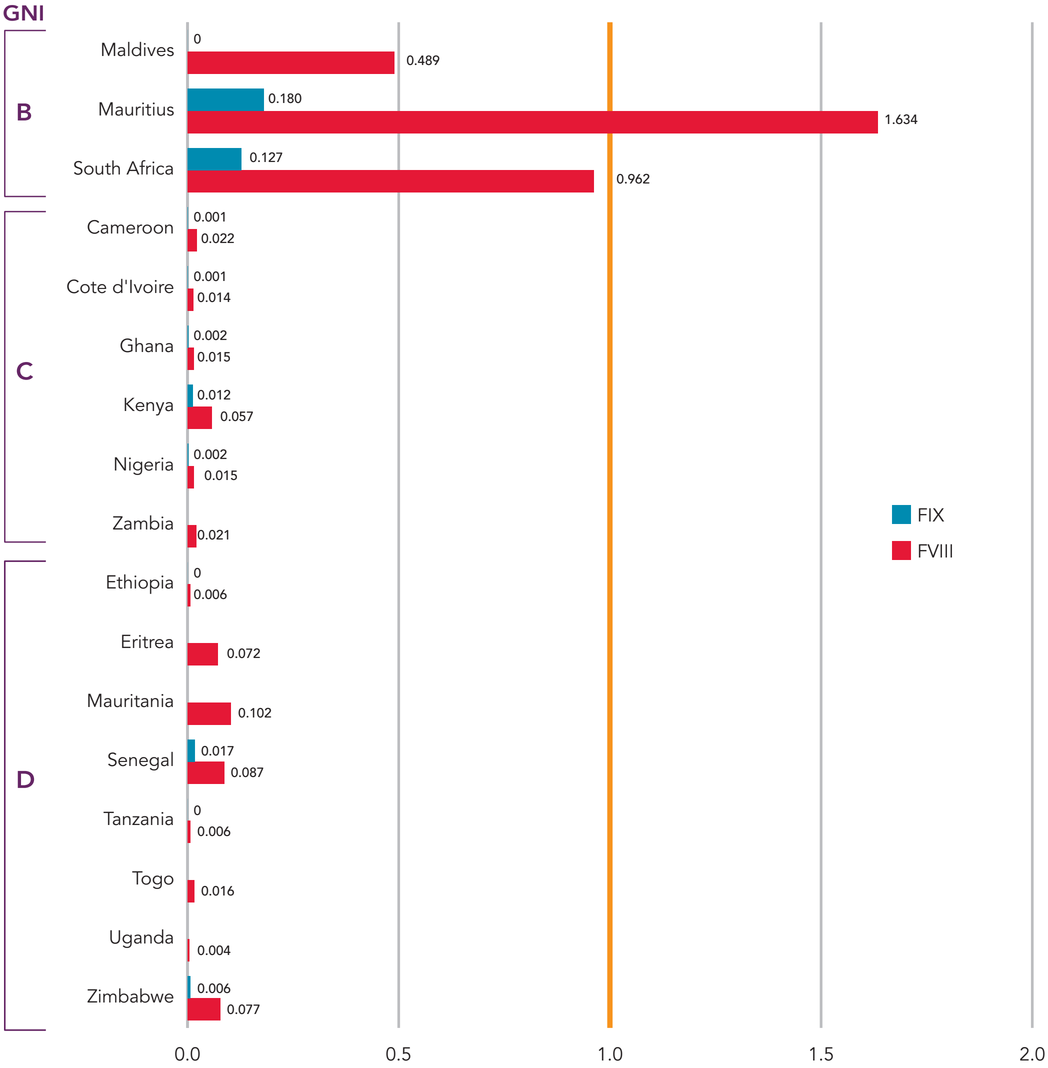
(Data from 79 countries.)



Economic category based on The World Bank Group 2015 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". (GNI in US dollars: D lower income, $0-$1,025; C lower middle income, $1,026 - $4,035; B upper middle income, $4,036 - $12,475; and A high income, $12,475 or more.)

Numbers in Figure B2 are calculated based on reported factor VIII use and the number of identified hemophilia A patients. We do not have data on individual treatment. WFH humanitarian aid donations are included.

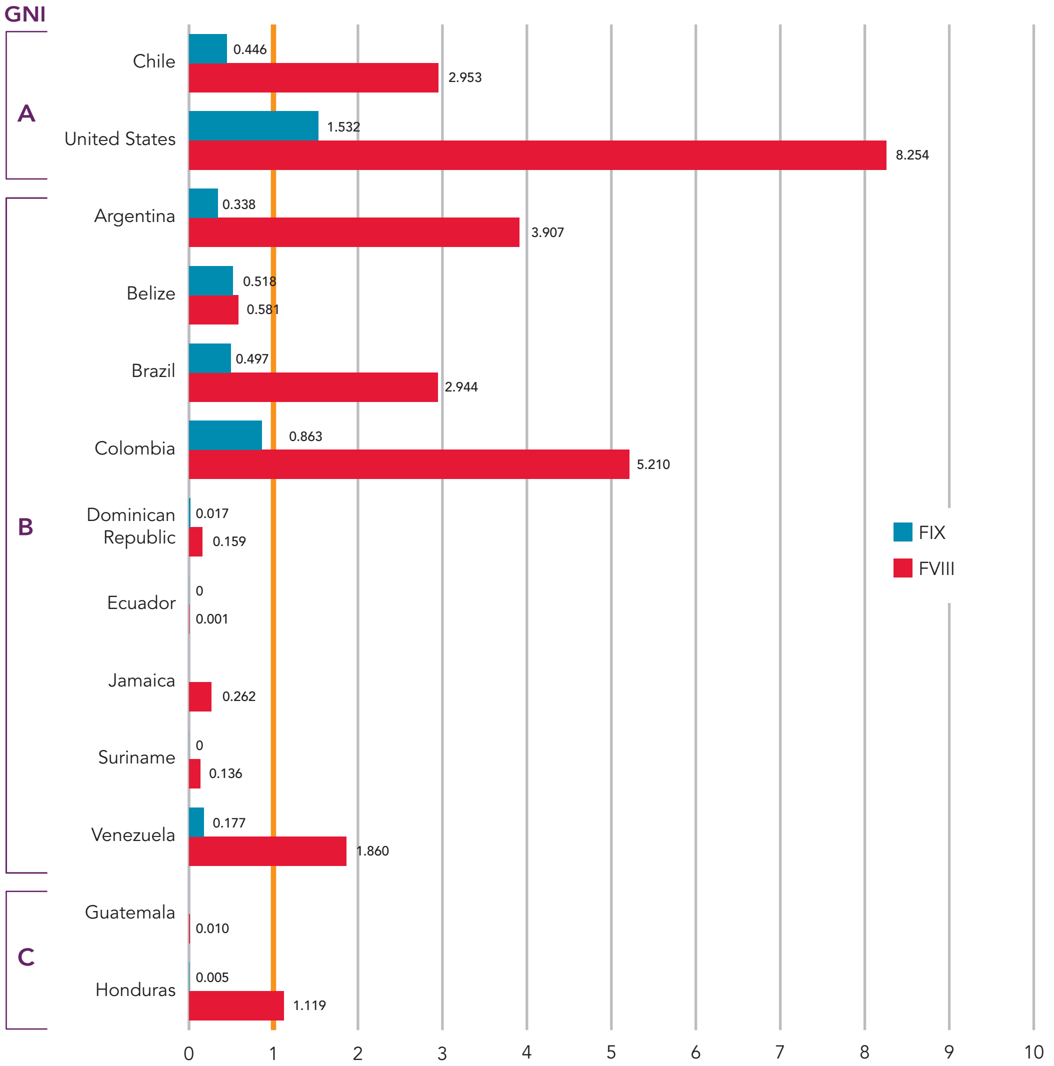
Figure C1. Mean per capita factor VIII and IX use in 2015 – regional and GNI comparisons of IU/total population: Africa



Economic category based on The World Bank Group 2015 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". (GNI in US dollars: D lower income, $0-$1,025; C lower middle income, $1,026 - $4,035; B upper middle income, $4,036 - $12,475; and A high income, $12,475 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 2015 questionnaire are included in these charts.

Figure C2. Mean per capita factor VIII and IX use in 2015 – regional and GNI comparisons of IU/total population: Americas



Economic category based on The World Bank Group 2015 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". (GNI in US dollars: D lower income, $0-$1,025; C lower middle income, $1,026 - $4,035; B upper middle income, $4,036 - $12,475; and A high income, $12,475 or more.) (Regions based on WHO regions.)

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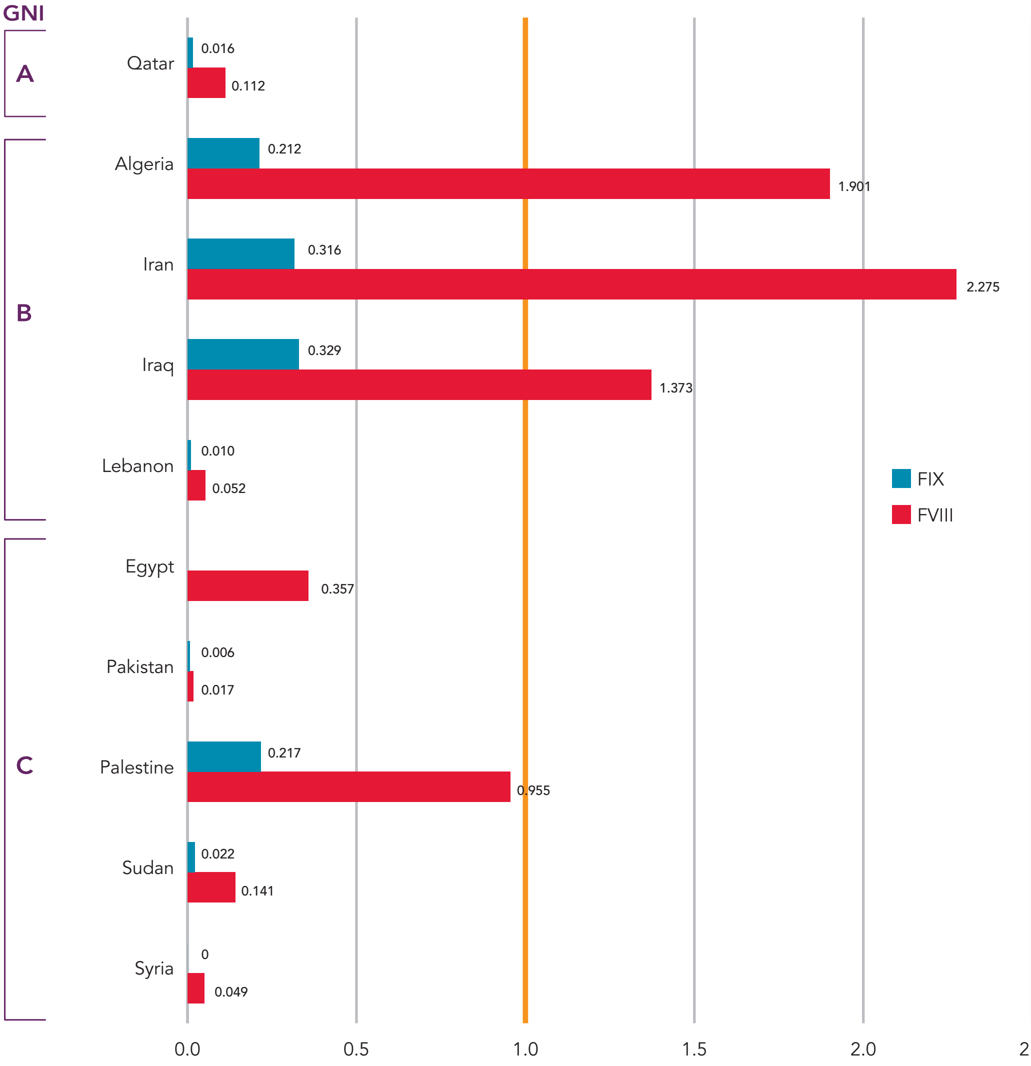
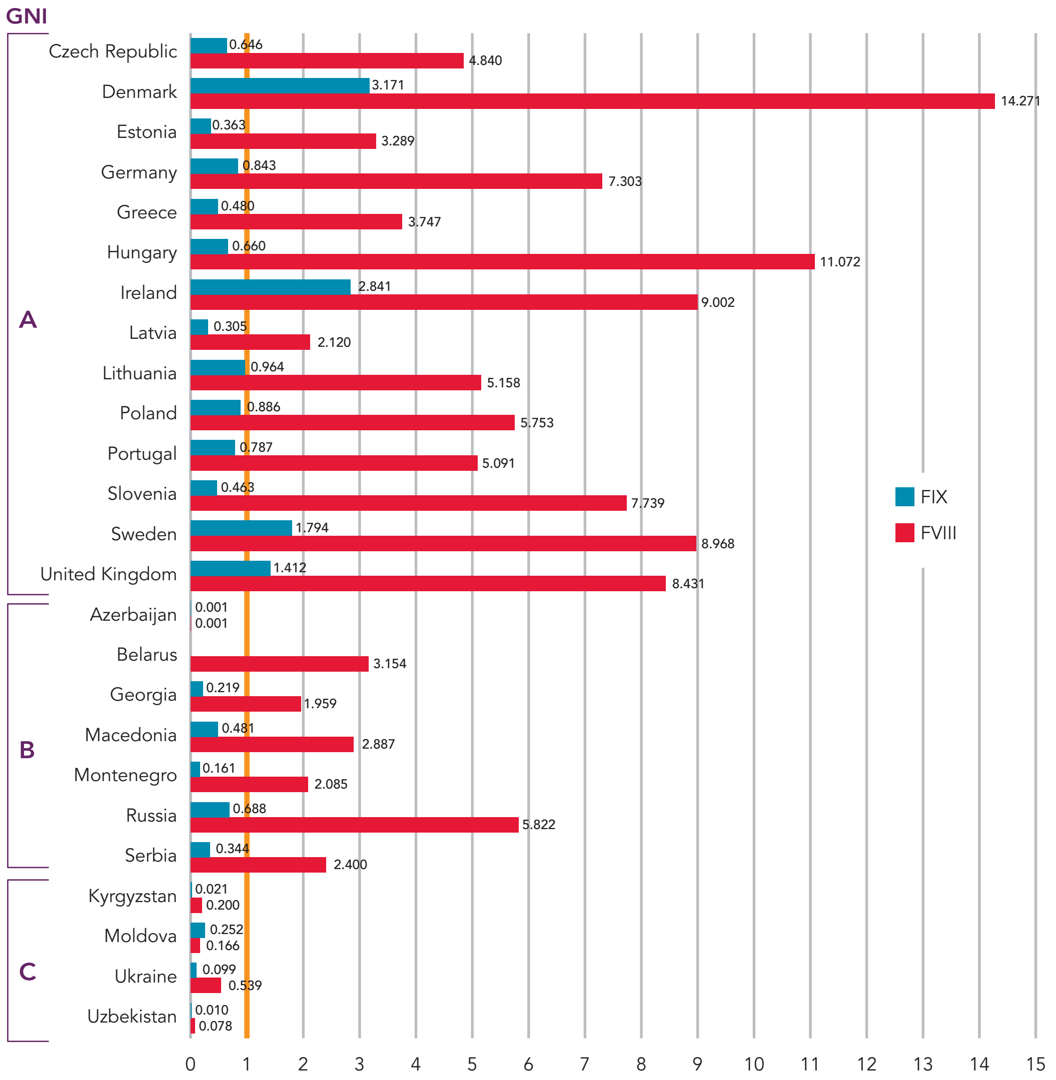
Figure C3. Mean per capita factor VIII and IX use in 2015 – regional and GNI comparisons of IU/total population: Eastern Mediterranean



Economic category based on The World Bank Group 2015 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". (GNI in US dollars: D lower income, $0-$1,025; C lower middle income, $1,026 - $4,035; B upper middle income, $4,036 - $12,475; and A high income, $12,475 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 2015 questionnaire are included in these charts.

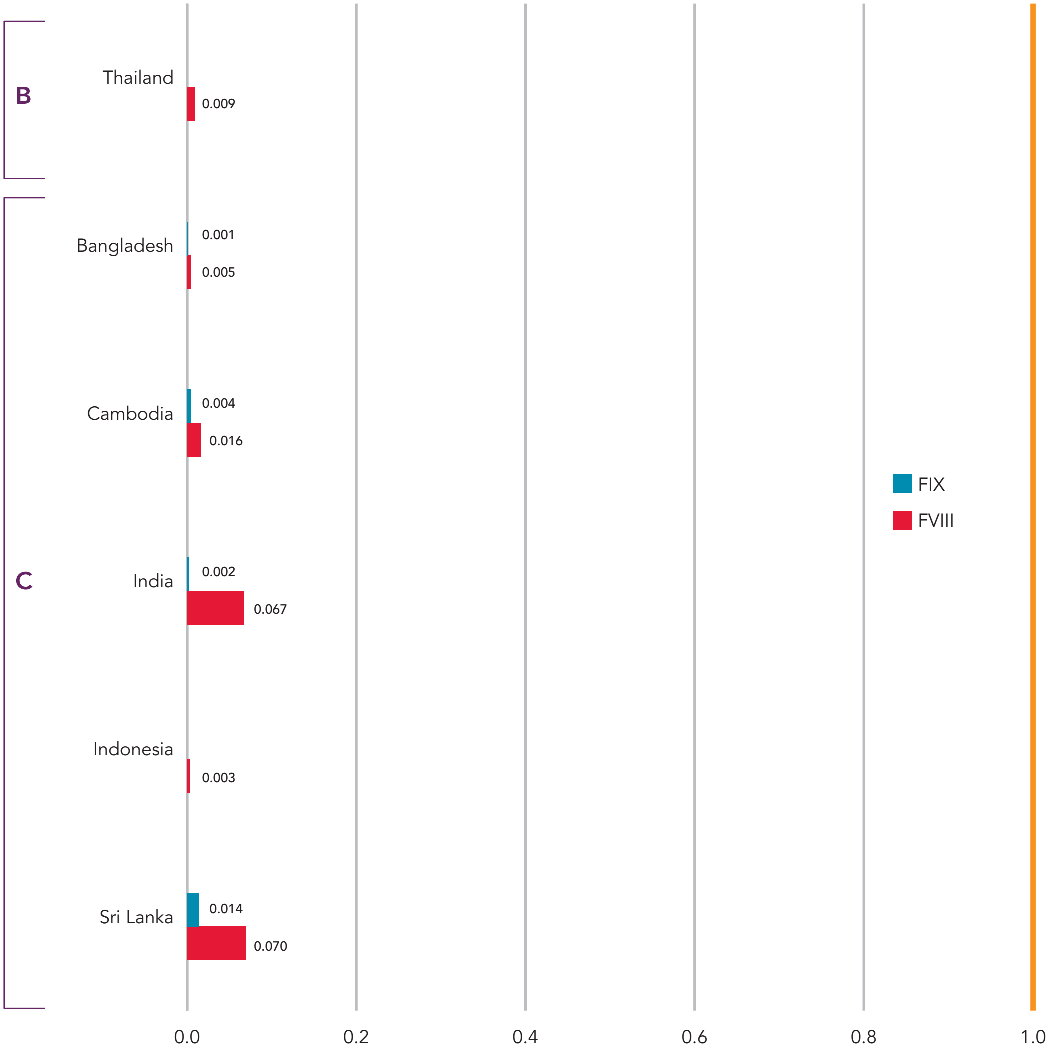
Figure C4. Mean per capita factor VIII and IX use in 2015 – regional and GNI comparisons of IU/total population: Europe



Economic category based on The World Bank Group 2015 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". (GNI in US dollars: D lower income, $0-$1,025; C lower middle income, $1,026 - $4,035; B upper middle income, $4,036 - $12,475; and A high income, $12,475 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 2015 questionnaire are included in these charts.

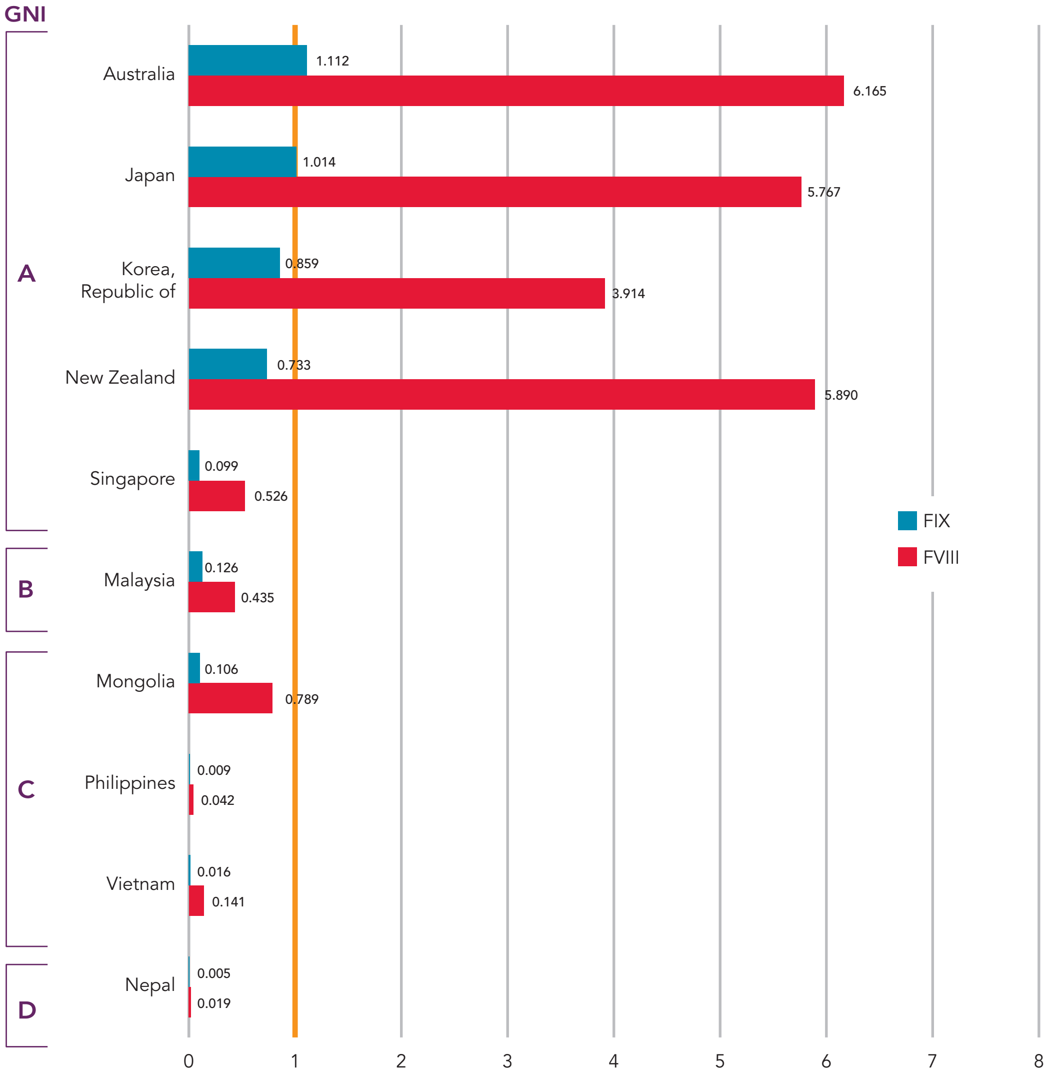
Figure C5. Mean per capita factor VIII and IX use in 2015 – regional and GNI comparisons of IU/total population: South-East Asia



Economic category based on The World Bank Group 2015 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". (GNI in US dollars: D lower income, $0-$1,025; C lower middle income, $1,026 - $4,035; B upper middle income, $4,036 - $12,475; and A high income, $12,475 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 2015 questionnaire are included in these charts.

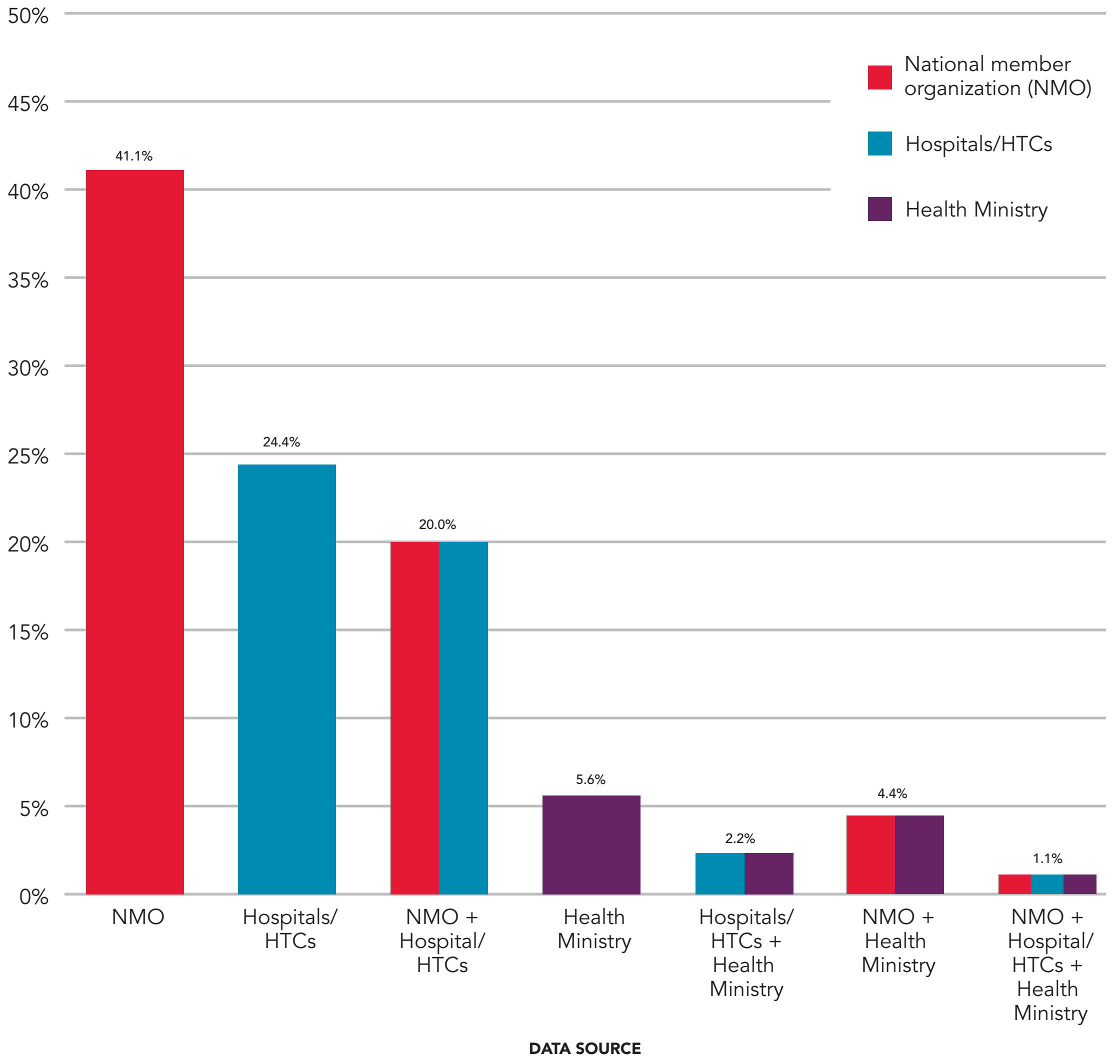
Figure C6. Mean per capita factor VIII and IX use in 2015 – regional and GNI comparisons of IU/total population: Western Pacific



Economic category based on The World Bank Group 2015 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". (GNI in US dollars: D lower income, $0-$1,025; C lower middle income, $1,026 - $4,035; B upper middle income, $4,036 - $12,475; and A high income, $12,475 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 2015 questionnaire are included in these charts.

Figure D. Data source

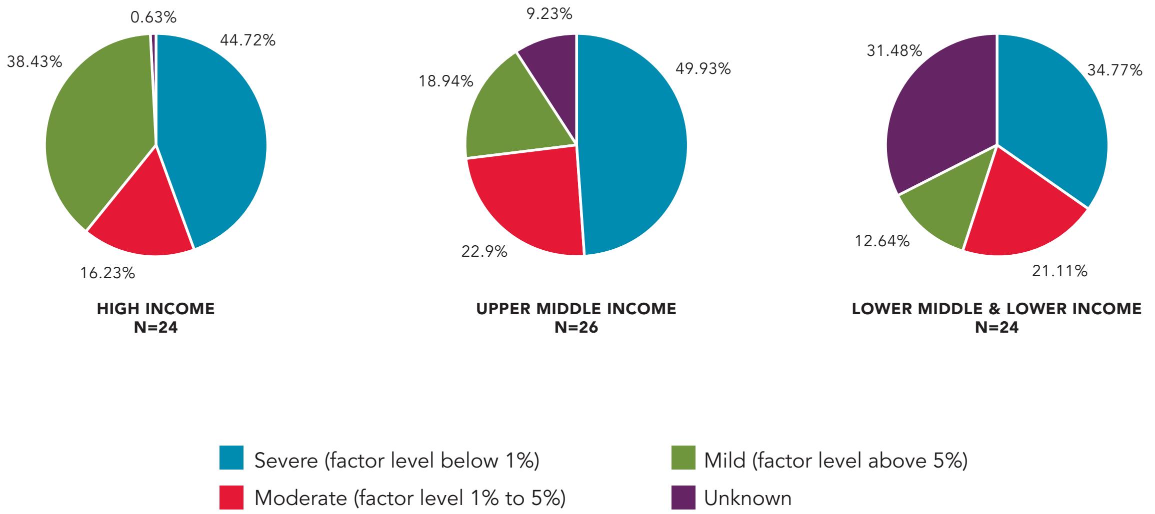


Members were asked the source of the numbers provided for the survey. Possible answers were: Hemophilia Society and/or national member organization (NMO) registry or database, Hospital(s)/HTC(s) registry or database, Health Ministry registry or database or Other. Many members used multiple sources to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

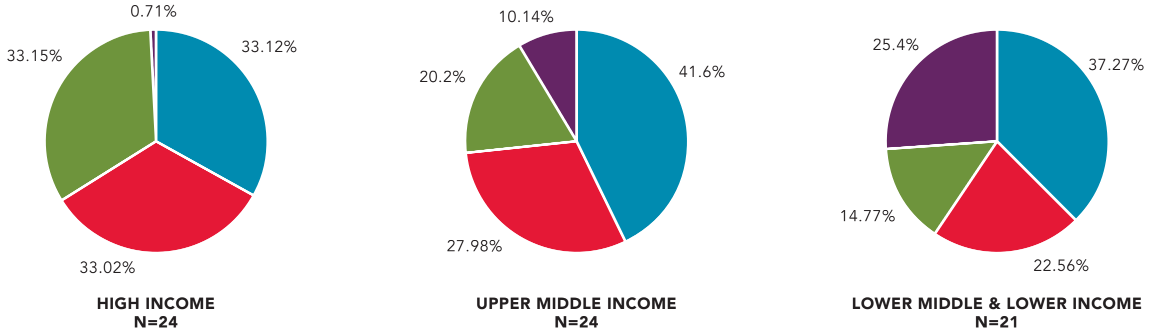
Figure E1. Severity in hemophilia males

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

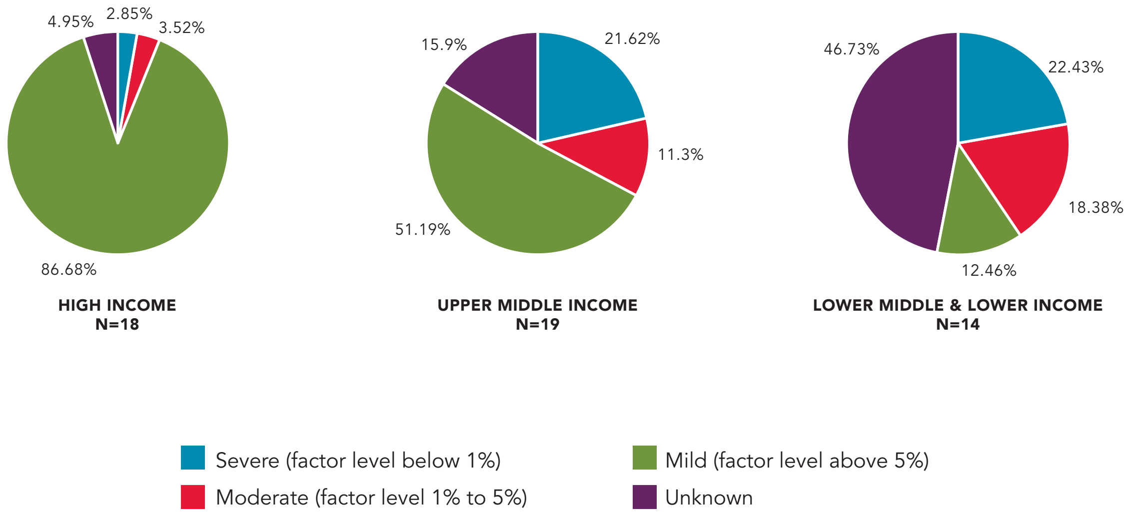


Economic category based on The World Bank Group 2015 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". (GNI in US dollars: D lower income, $0-$1,025; C lower middle income, $1,026 - $4,035; B upper middle income, $4,036 - $12,475; and A high income, $12,475 or more.) (Regions based on WHO regions.)

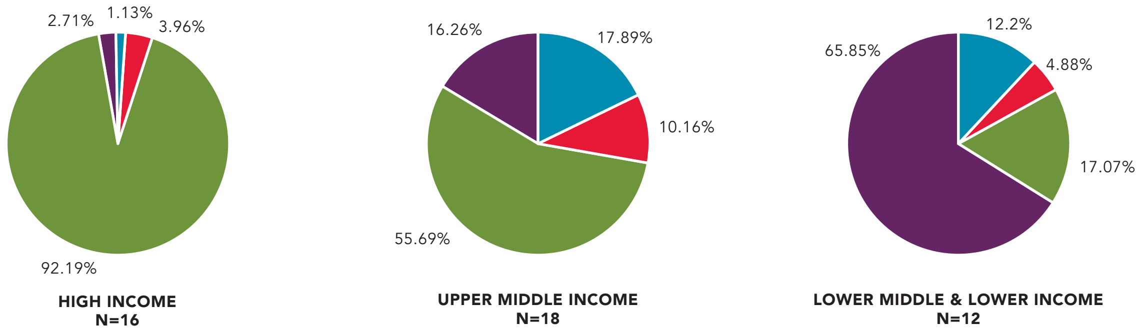
Figure E2. Severity in hemophilia females

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 The World Bank Group 2015 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". (GNI in US dollars: D lower income, $0-$1,025; C lower middle income, $1,026 - $4,035; B upper middle income, $4,036 - $12,475; and A high income, $12,475 or more.) (Regions based on WHO regions.)

Table 5. Countries included in the Report on the Annual Global Survey 2015

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 2015 survey report, 90 countries submitted data for 2015. Countries in **BOLD** reported data for 2015.

Data from 2014 was used for 21 countries. 2014 surveys are only used for reporting the number of patients identified – all other numbers in this report are from 2015 only.

Afghanistan	2014
Albania	2014
Algeria	2015
Argentina	2015
Australia	2015
Austria	2015
Azerbaijan	2015
Bahrain	2014
Bangladesh	2015
Belarus	2015
Belgium	2015
Belize	2015
Bolivia	2014
Brazil	2015
Cambodia	2015
Cameroon	2015
Canada	2014
Chile	2015
China	2015
Colombia	2015
Costa Rica	2015
Cote d'Ivoire	2015
Cuba	2014
Czech Republic	2015
Denmark	2015
Dominican Republic	2015
Ecuador	2015
Egypt	2015
Eritrea	2015
Estonia	2015
Ethiopia	2015
Finland	2014
France	2015
Georgia	2015
Germany	2015
Ghana	2015
Greece	2015
Guatemala	2015
Honduras	2015
Hong Kong (China)	2015
Hungary	2015
India	2015
Indonesia	2015
Iran	2015
Iraq	2015
Ireland	2015
Italy	2014
Jamaica	2015
Japan	2015
Jordan	2014
Kenya	2015
Korea, Republic of	2015
Kyrgyzstan	2015
Latvia	2015
Lebanon	2015
Lesotho	2014
Lithuania	2015
Macedonia	2015
Malaysia	2015
Maldives	2015
Mauritania	2015
Mauritius	2015
Mexico	2014
Moldova	2015
Mongolia	2015
Montenegro	2015
Morocco	2014
Nepal	2015
Netherlands	2015
New Zealand	2015
Nigeria	2015
Norway	2014
Pakistan	2015
Palestine	2015
Panama	2014
Paraguay	2014
Peru	2015
Philippines	2015
Poland	2015
Portugal	2015
Qatar	2015
Romania	2014
Russia	2015
Saudi Arabia	2014
Senegal	2015
Serbia	2015
Singapore	2015
Slovak Republic	2014
Slovenia	2015
South Africa	2015
Sri Lanka	2015
Sudan	2015
Suriname	2015
Sweden	2015
Syria	2015
Tanzania	2015
Thailand	2015
Togo	2015
Tunisia	2014
Turkey	2014
Uganda	2015
Ukraine	2015
United Arab Emirates	2015
United Kingdom	2015
United States	2015
Uruguay	2014
Uzbekistan	2015
Venezuela	2015
Vietnam	2015
Zambia	2015
Zimbabwe	2015

Table 6. Population statistics

Please 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 2015. For countries that did not report population statistics for 2015 but did report during the year 2014, we used the most recent number of patients reported. 2014 surveys are only used for reporting the number of patients identified – all other numbers in this report are from 2015 only.

The source of population data from 1999 to 2014 was The World Factbook, Central Intelligence Agency. As of 2015, population data is sourced from The World Bank Group.

	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	39,666,519	2,131	238	498
Argentina	43,416,755	2,561	404	10
Australia	23,781,169	2,451	2,012	648
Austria	8,611,088	786	Not Known	Not Known
Azerbaijan	9,651,349	1,247	192	86
Bahrain	1,314,089	28	Not Known	22
Bangladesh	160,995,642	748	2	3
Belarus	9,513,000	564	192	48
Belgium	11,285,721	1,177	1,810	424
Belize	359,287	16	Not Known	Not Known
Bolivia	10,631,486	66	Not Known	Not Known
Brazil	207,847,528	11,857	7,223	2,576
Cambodia	15,577,899	131	2	4
Cameroon	23,344,179	138	10	Not Known
Canada	34,834,841	3,822	4,180	1,899
Chile	17,948,141	1,547	483	473
China	1,371,220,000	13,624	64	78
Colombia	48,228,704	1,812	1,143	254
Costa Rica	4,807,850	211	71	36
Cote d'Ivoire	22,701,556	79	3	3
Cuba	11,047,251	469	301	2,803
Czech Republic	10,551,219	1,067	810	91

	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Denmark	5,676,002	490	249	132
Dominican Republic	10,528,391	210	31	44
Ecuador	16,144,363	122	44	4
Egypt	91,508,084	5,420	528	1,168
Eritrea	5,869,869	50	Not Known	Not Known
Estonia	1,311,998	106	92	65
Ethiopia	99,390,750	204	17	1
Finland	5,268,799	227	508	Not Known
France	66,808,385	6,848	1,865	476
Georgia	3,679,000	305	32	21
Germany	81,413,145	4,443	3,487	Not Known
Ghana	27,409,893	148	7	Not Known
Greece	10,823,732	1,025	1,078	379
Guatemala	16,342,897	221	21	4
Honduras	8,075,060	301	9	5
Hong Kong (China)	7,305,700	131	2	7
Hungary	9,844,686	1,103	1,430	461
India	1,311,050,527	17,346	483	305
Indonesia	257,563,815	1,749	3	Not Known
Iran	79,109,272	6,015	1,438	2,871
Iraq	36,423,395	1,276	304	358
Ireland	4,640,703	839	1,273	977
Italy	61,680,122	4,813	2,840	2,140
Jamaica	2,725,941	45	Not Known	Not Known
Japan	126,958,472	6,050	1,177	380
Jordan	7,930,491	349	252	246
Kenya	46,050,302	625	42	11
Korea, Republic of	50,617,045	2,063	116	124
Kyrgyzstan	5,957,000	300	9	3
Latvia	1,978,440	153	120	5
Lebanon	5,850,743	189	107	69
Lesotho	1,942,008	24	Not Known	Not Known
Lithuania	2,910,199	168	302	18
Macedonia	2,078,453	315	167	20

	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Malaysia	30,331,007	1,341	614	279
Maldives	409,163	15	Not Known	Not Known
Mauritania	4,067,564	38	2	Not Known
Mauritius	1,262,605	66	0	7
Mexico	120,286,655	4,938	256	32
Moldova	3,554,150	230	6	Not Known
Mongolia	2,959,134	88	13	Not Known
Montenegro	622,388	45	3	5
Morocco	32,987,206	1,116	7	Not Known
Nepal	28,513,700	542	3	14
Netherlands	16,936,520	Not Known	Not Known	Not Known
New Zealand	4,595,700	441	224	43
Nigeria	182,201,962	275	1	Not Known
Norway	5,147,792	443	880	77
Pakistan	188,924,874	828	172	78
Palestine	4,422,143	293	35	7
Panama	3,608,431	288	459	54
Paraguay	6,703,860	416	5	1
Peru	31,376,670	887	171	19
Philippines	100,699,395	1,477	32	Not Known
Poland	37,999,494	2,808	1,715	581
Portugal	10,348,648	703	51	15
Qatar	2,235,355	50	30	25
Romania	21,729,871	1,635	111	14
Russia	144,096,812	6,793	1,491	569
Saudi Arabia	27,345,986	389	172	149
Senegal	15,129,273	185	7	11
Serbia	7,098,247	532	279	42
Singapore	5,535,002	244	78	97
Slovak Republic	5,443,583	589	594	960
Slovenia	2,063,768	233	184	80
South Africa	54,956,920	2,184	630	220
Sri Lanka	20,966,000	788	32	23
Sudan	40,234,882	916	238	281

	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Suriname	542,975	20	5	0
Sweden	9,798,871	1,068	1,512	513
Syria	18,502,413	660	70	73
Tanzania	53,470,420	73	Not Known	Not Known
Thailand	67,959,359	405	68	59
Togo	7,304,578	22	Not Known	Not Known
Tunisia	10,937,521	419	119	252
Turkey	81,619,392	5,738	1,119	2,290
Uganda	39,032,383	98	3	Not Known
Ukraine	45,198,200	2,600	470	Not Known
United Arab Emirates	9,156,963	100	40	31
United Kingdom	65,138,232	7,840	10,586	7,396
United States	321,418,820	18,596	13,845	6,567
Uruguay	3,332,972	192	214	32
Uzbekistan	31,299,500	1,433	91	33
Venezuela	31,108,083	2,697	933	986
Vietnam	91,703,800	2,551	75	192
Zambia	16,211,767	70	Not Known	Not Known
Zimbabwe	15,602,751	142	Not Known	Not Known
Total	**6,679,179,772**	**187,183**	**74,819**	**42,360**

Table 7. Distribution of reported bleeding disorders by country

Please 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 2015.

	Hemophilia A	Hemophilia B	Hemophilia type unknown	VWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXII	Bleeding Disorder: Type Unknown	Glanzmanns thrombasthenia	Bernard Soulier	Platelet Disorders: Other/Unknown
Afghanistan	273	15														
Albania	132	18		1				1	1			1				
Algeria	1,776	355		238	32	5	56	25	269	21	12	21		32	25	
Argentina	2,216	345		404				1	2		1	1		2		3
Australia	1,968	483		2,012	49		11		63	17	217	36		18	5	232
Austria	660	126														
Azerbaijan	1,119	128		192		8	5	18	17	15	8	1	5	4	5	
Bahrain	24	4	0		0	3	2	2	1	5	0	3	0	6		
Bangladesh	633	109	6	2	2	0	0	0	0	0	0	1	0	0	0	0
Belarus	455	109		192	0	0			19	3	26					
Belgium	945	225	7	1,810	2	2	20		110	7	119	4	25	19	2	114
Belize	11	5														
Bolivia	57	9														
Brazil	9,912	1,945	0	7,223	97	15	178	32	890	104	195	64		543	68	390
Cambodia	114	17		2								1		3		
Cameroon	123	15		10												
Canada	3,110	712		4,180	89	13	71	4	329	37	397	55	61	61	29	753
Chile	1,295	138	114	483			26	5	215	26	35			5	4	157
China	11,837	1,787		64	31		4	6	9	5	15	3		5		
Colombia	1,484	328	0	1,143	16	6	17	6	68	1	37	24	36	15	2	26
Costa Rica	179	32		71	1	0	1	0	17	8	6	3				
Cote d'Ivoire	72	7	0	3					1	2						
Cuba	401	68	0	301	2	1	2	0	1	0	16	7	21	3	0	2,750
Czech Republic	931	136	0	810	0	1	5	0	39	4	21	2	19			
Denmark	388	102		249	1	1	3	0	53	7	13	6		13	6	29
Dominican Republic												3		3		
Ecuador	115	7	0	44	0	0	2	0	1	0	0	0	0	1	0	0
Egypt	4,358	1,062		528	144	8	168	8	123	110	92	40		457	18	
Eritrea	45	5	0	0												
Estonia	96	10		92	3		2	1	30		5		15		1	8
Ethiopia	72	7	125	17										1		

	Hemophilia A	Hemophilia B	Hemophilia type unknown	VWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXII	Bleeding Disorder: Type Unknown	Glanzmanns thrombasthenia	Bernard Soulier	Platelet Disorders: Other/Unknown
Finland	141	30	56	508												
France	5,581	1,267	0	1,865	40	1	49	13	157	23	168	25				
Georgia	258	47		32			1		8			2	6	4		
Germany	3,768	675		3,487												
Ghana	91	7	50	7												
Greece	846	179	0	1,078	19	2	27	0	121	9	90	13	0	16	13	69
Guatemala	179	21	21	21					3		1					
Honduras	274	27		9					3		1	1				
Hong Kong (China)	101	23	7	2					2	2						3
Hungary	881	222		1,430	15	1	21	0	296	22	77	1	0	0	0	28
India	14,508	2,127	711	483	12	7	49	4	46	37	31	79	0	20	20	
Indonesia	849	99	801	3												
Iran	4,944	1,071	0	1,438	132	23	191	222	629	167	201	226	169	516	105	290
Iraq	946	330	0	304	54	2	9	4	80	23	12	49	0	0	0	125
Ireland	601	238	0	1,273	0	0	150	0	156	131	218	11	0	8	3	300
Italy	3,992	821		2,840		20	159	36	747	105	433	128				512
Jamaica	41	4														
Japan	4,986	1,064		1,177	70	7	36	9	100	22	39	70	27			
Jordan	267	82		252		4	13		46	25	42	12		103	1	
Kenya	509	116	0	42	0	0	0	0	1	0	0	0	0	0	0	10
Korea, Republic of	1,654	409		116	6		6	7	37	2	19	5	42			
Kyrgyzstan	273	27		9	1	1								1		
Latvia	129	24		120					5							
Lebanon	146	43		107	34		9	1	7	5	5	2		1		5
Lesotho	22	2														
Lithuania	145	22	1	302					11	2	3	2				
Macedonia	207	108		167					2		1	5	12			
Malaysia	1,145	196		614	4	3	20	1	49	23	58	16	0	49	1	55
Maldives	12	3														
Mauritania	29	9		2												
Mauritius	54	9	3	0					3	1	1					2
Mexico	3,993	608	337	256	1	0	2	0	18	3	3	1	2	1	0	1
Moldova	199	21		6												
Mongolia	65	23		13												
Montenegro	41	4		3					1		1	3				
Morocco	904	180	32	7												
Nepal	467	75		3		1	1		1	9		2				

	Hemophilia A	Hemophilia B	Hemophilia type unknown	VWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXII	Bleeding Disorder: Type Unknown	Glanzmanns thrombasthenia	Bernard Soulier	Platelet Disorders: Other/Unknown
Netherlands																
New Zealand	361	80		224	2	1			7	1	2	5	9	2	1	13
Nigeria	190	4	81	1												
Norway	344	99	0	880	2	1	3	0	27	0	1	4	0	10	3	26
Pakistan	705	123	0	172	6	2	12	6	13	13	0	12	1	11	2	0
Palestine	180	40	73	35		3						2		2		
Panama	256	32	0	459	0	0	0	0	9	16	0	0	0	5	1	23
Paraguay	400	10	1	5									1			
Peru	712	125	50	171	1	0	1	0	7	1	5	1	2	1	0	0
Philippines	967	173	337	32												
Poland	2,389	419		1,715		1	26	3	245	23	61	10		24	7	181
Portugal	539	112	52	51	2	0	3	0	2	1	6	1				
Qatar	47	3		30					3			2		5		1
Romania	1,438	197		111	1			2	2	2	2		1		1	
Russia	5,801	992		1,491									569			
Saudi Arabia	314	75	0	172	1	11	6	1	12	4	10	33	0	67	4	0
Senegal	167	18	0	7			1		3	1		1				5
Serbia	451	81		279	4		1	2	22		7	4	1		1	
Singapore	200	44		78			20		11	3	48	3	12			
Slovak Republic	517	72	0	594	78	0	71	2	673	35	50	3	0	10	15	23
Slovenia	205	28		184	3		12	2	15	2	19	1	4	7		15
South Africa	1,822	362	0	630	8	0	44	5	18	9	26	8	6	19	26	51
Sri Lanka	652	136		32			9		1		5					8
Sudan	766	150		238	29		41	2	26	25	4	25	2	123		
Suriname	20	0	0	5												
Sweden	860	208		1,512	0	3	2	2	136	19	69	9	1	9	13	250
Syria	591	69	0	70	14	0	5	28	12	3	0	0	0	11	0	0
Tanzania	45	10	18													
Thailand	348	57		68				1	14	2				39		3
Togo	11	5	6													
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	83	15		3												
Ukraine																
United Arab Emirates	85	15		40					10	1				15	4	1
United Kingdom	6,390	1,450	0	10,586	565	14	199	27	1,115	237	2,794	66	0	123	85	2,171

	Hemophilia A	Hemophilia B	Hemophilia type unknown	VWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXII	Bleeding Disorder: Type Unknown	Glanzmanns thrombasthenia	Bernard Soulier	Platelet Disorders: Other/Unknown
United States	14,175	4,421	0	13,845	145	36	272	13	1,057	123	666	140	0	180	41	3,894
Uruguay	173	19		214	1		1	2	7	2	10		3			6
Uzbekistan	1,297	136		91	1	2			10		6			10	1	3
Venezuela	2,141	556		933	20	66	33	27	163	108	376	16	2	15	4	156
Vietnam	2,079	472	0	75	6	3	4	10	24	16	7	5	47	70		0
Zambia	70	0	0													
Zimbabwe	129	13	0													
Total	**151,159**	**30,310**	**2,889**	**74,318**	**1,777**	**278**	**2,122**	**547**	**9,330**	**1,799**	**6,866**	**1,485**	**2,074**	**2,748**	**527**	**12,748**

Table 8. Gender distribution

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

Disorders	Countries reporting	Total patients identified	Male	Percent male	Female	Percent female	Gender not known	Percent not known
Hemophilia A	**108**	151,159	137,741	**91**	3,988	**3**	9,430	**6**
Hemophilia B	**108**	30,310	27,057	**89**	1,328	**4**	1,925	**6**
Hemophilia type unknown	**50**	2,889	1,849	**64**	127	**4**	913	**32**
von Willebrand disease (VWD)	**96**	74,318	24,469	**33**	38,930	**52**	10,919	**15**
Factor I deficiency	**53**	1,777	710	**40**	887	**50**	180	**10**
Factor II deficiency	**49**	278	123	**44**	129	**46**	26	**9**
Factor V deficiency	**59**	2,122	874	**41**	1,009	**48**	239	**11**
Factor V+VIII deficiency	**55**	547	285	**52**	221	**40**	41	**7**
Factor VII deficiency	**77**	9,330	4,448	**48**	4,306	**46**	576	**6**
Factor X deficiency	**64**	1,799	810	**45**	773	**43**	216	**12**
Factor XI deficiency	**64**	6,838	2,977	**44**	3,620	**53**	241	**4**
Factor XIII deficiency	**66**	1,485	813	**55**	580	**39**	92	**6**
Bleeding disorder: type unknown	**47**	2,074	1,052	**51**	402	**19**	620	**30**
Platelet disorders: Glanzmanns thrombasthenia	**55**	2,748	953	**35**	1,084	**39**	711	**26**
Platelet disorders: Bernard Soulier syndrome	**43**	527	230	**44**	250	**47**	47	**9**
Platelet disorders: other or unknown	**49**	12,748	4,153	**33**	7,650	**60**	945	**7**

A woman who has less than 40 percent of the normal level of clotting factor would be considered a person with hemophilia. A woman with more than 40 percent clotting factor is considered a carrier and is not included in this report.

Table 9. 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.

Please note: a 0 indicates that the member organization reported the number zero, a blank space indicates that no number was reported.

	Hemophilia A inhibitors (total)	Hemophilia A inhibitors (new cases in 2015)	Hemophilia B inhibitors (total)	Hemophilia B inhibitors (new cases in 2015)
Algeria	39	9	0	0
Argentina	113	6	7	1
Australia	64	7	3	0
Austria	24	0	2	0
Azerbaijan	21	3		
Belarus	48		3	
Belize	0	0	0	0
Brazil	279	33	15	0
Cambodia	2	1		
Cameroon	7	0	1	0
Chile	25	1	1	0
Colombia	106			
Costa Rica	20	0	1	0
Czech Republic	19	3	2	0
Denmark	13	1	1	0
Dominican Republic	10	6		
Ecuador	0	1	0	0
Egypt	52	13	2	0
Eritrea	3			
Estonia	4	0		
France	113	5	3	0
Georgia	8	1		
Germany	114		11	
Ghana	2	0	0	0
Greece	22	2	3	0
Guatemala	7			

	Hemophilia A inhibitors (total)	Hemophilia A inhibitors (new cases in 2015)	Hemophilia B inhibitors (total)	Hemophilia B inhibitors (new cases in 2015)
Honduras	3	1		
Hong Kong (China)	7		1	
Hungary	31	10	1	0
Indonesia	92			
Iran	247	47	16	5
Iraq	80	20	3	0
Ireland	16	3	2	0
Jamaica	5	0	0	0
Japan	112		9	
Kenya	3	0	0	0
Korea, Republic of	44	2	7	1
Latvia	2	0	1	0
Lebanon	6		0	0
Lithuania	8	1		
Macedonia	2	0	2	0
Malaysia	103	6	3	0
Mauritania	1			
Mauritius	1	1	0	0
Moldova	1	1	0	0
Montenegro	1	1	0	0
Nepal	10	2		
New Zealand	16		0	
Nigeria	1			
Pakistan	11	5	0	0
Peru	15	0	1	0
Philippines	15	3	1	0
Poland	149		4	
Qatar	5	2	0	0
Russia	215		3	
Senegal	7	2	0	0
Serbia	18	1	0	0
Singapore	13	0	2	0
Slovenia	2	0	0	0
South Africa	168	5	12	1

	Hemophilia A inhibitors (total)	Hemophilia A inhibitors (new cases in 2015)	Hemophilia B inhibitors (total)	Hemophilia B inhibitors (new cases in 2015)
Sudan	7	1	1	1
Suriname	0	0		
Sweden	26	3	5	0
Syria	35	0	1	0
Thailand	52	5	1	0
United Arab Emirates	7	2	0	0
United Kingdom	218	26	13	2
Uzbekistan	37			
Venezuela	101	4	3	0
Vietnam	91	15	7	2
Zimbabwe		4		0
Total	**3,099**	**265**	**154**	**36**

Table 10. Age distribution: Hemophilia A

(78 countries reported age data.)

	Hemophilia A	0–4	5–13	14–18	19–44	45+	Age Not Known
Argentina	2,216	5%	17%	9%	46%	20%	3%
Australia	1,968	6%	14%	7%	40%	32%	0%
Austria	660	3%	10%	8%	44%	35%	0%
Bangladesh	633	7%	30%	24%	35%	4%	0%
Belarus	455	1%	11%	6%	49%	30%	3%
Belgium	945	2%	14%	7%	35%	42%	1%
Belize	11	9%	27%	27%	36%	0%	0%
Brazil	9,912	5%	16%	11%	50%	18%	0%
Cambodia	114	18%	44%	18%	20%	0%	0%
Cameroon	123	11%	39%	14%	28%	8%	0%
Chile	1,295	2%	17%	13%	54%	14%	0%
China	11,837	1%	19%	13%	51%	15%	1%
Colombia	1,484	8%	27%	14%	36%	15%	0%
Costa Rica	179	7%	20%	13%	45%	9%	6%
Cote d'Ivoire	72	19%	22%	29%	24%	6%	0%
Czech Republic	931	5%	11%	7%	46%	31%	0%
Denmark	388	3%	11%	11%	37%	17%	21%
Ecuador	115	0%	3%	10%	67%	20%	1%
Egypt	4,358	4%	36%	3%	13%	2%	42%
Eritrea	45	4%	18%	11%	64%	2%	0%
Estonia	96	5%	9%	4%	61%	20%	0%
Ethiopia	72	4%	35%	22%	29%	3%	7%
France	5,581	5%	15%	9%	42%	29%	0%
Georgia	258	8%	18%	7%	47%	20%	0%
Ghana	91	15%	8%	24%	22%	3%	27%
Greece	846	3%	7%	8%	45%	36%	0%
Guatemala	179	6%	16%	18%	47%	7%	7%
Honduras	274	9%	29%	15%	36%	3%	8%
Hong Kong (China)	101	5%	22%	6%	55%	11%	1%
Hungary	881	3%	8%	6%	44%	39%	0%

	Hemophilia A	0–4	5–13	14–18	19–44	45+	Age Not Known
India	14,508	1%	14%	11%	35%	7%	31%
Iran	4,944	3%	13%	8%	58%	18%	0%
Iraq	946	23%	38%	19%	18%	3%	0%
Ireland	601	9%	17%	9%	38%	28%	0%
Jamaica	41	5%	12%	20%	37%	27%	0%
Kenya	509	31%	28%	15%	9%	13%	4%
Korea, Republic of	1,654	4%	13%	10%	52%	20%	0%
Kyrgyzstan	273	5%	13%	21%	57%	4%	0%
Latvia	129	5%	12%	7%	47%	27%	2%
Lebanon	146	5%	19%	11%	49%	16%	0%
Malaysia	1,145	28%	21%	5%	9%	2%	36%
Maldives	12	8%	33%	8%	33%	8%	8%
Mauritania	29	7%	31%	7%	17%	3%	34%
Mauritius	54	0%	17%	11%	39%	26%	7%
Moldova	199	0%	5%	9%	13%	73%	0%
Mongolia	65	22%	31%	6%	37%	5%	0%
Montenegro	41	7%	17%	10%	32%	34%	0%
Nepal	467	4%	17%	36%	33%	11%	0%
New Zealand	361	3%	16%	7%	39%	22%	12%
Nigeria	190	11%	25%	10%	24%	2%	28%
Pakistan	705	7%	27%	17%	38%	7%	4%
Palestine	180	5%	27%	17%	43%	8%	1%
Peru	712	3%	19%	12%	46%	12%	9%
Philippines	967	2%	12%	8%	50%	7%	20%
Poland	2,389	2%	7%	5%	50%	36%	1%
Portugal	539	1%	9%	8%	41%	33%	8%
Qatar	47	21%	19%	26%	32%	2%	0%
Senegal	167	17%	35%	15%	29%	5%	0%
Serbia	451	3%	12%	9%	45%	30%	0%
Singapore	200	5%	9%	8%	45%	35%	0%
Slovenia	205	3%	9%	2%	40%	38%	7%
South Africa	1,822	5%	17%	10%	44%	22%	3%
Sudan	766	18%	33%	15%	31%	3%	0%
Suriname	20	0%	5%	0%	85%	10%	0%

	Hemophilia A	0–4	5–13	14–18	19–44	45+	Age Not Known
Sweden	860	1%	6%	3%	20%	15%	55%
Syria	591	12%	29%	16%	37%	5%	2%
Tanzania	45	4%	33%	11%	16%	2%	33%
Thailand	348	2%	13%	14%	69%	3%	0%
Togo	11	0%	45%	18%	36%	0%	0%
Uganda	83	27%	37%	11%	18%	4%	4%
United Arab Emirates	85	24%	22%	29%	25%	0%	0%
United Kingdom	6,390	6%	12%	8%	38%	36%	0%
United States	14,175	9%	22%	13%	39%	17%	0%
Uzbekistan	1,297	4%	19%	18%	54%	6%	0%
Venezuela	2,141	4%	13%	9%	39%	16%	19%
Vietnam	2,079	12%	21%	15%	38%	8%	6%
Zambia	70	11%	17%	9%	11%	3%	49%
Zimbabwe	129	7%	18%	18%	46%	4%	8%

Table 11. Age distribution: Hemophilia B

(78 countries reported age data.)

	Hemophilia B	0–4	5–13	14–18	19–44	45+	Age Not Known
Argentina	345	6%	19%	8%	44%	17%	6%
Australia	483	4%	14%	6%	42%	34%	0%
Austria	126	3%	13%	7%	44%	33%	0%
Bangladesh	109	7%	38%	28%	26%	2%	0%
Belarus	109	2%	10%	6%	50%	29%	4%
Belgium	225	5%	11%	5%	33%	46%	1%
Belize	5	0%	0%	40%	60%	0%	0%
Brazil	1,945	4%	16%	13%	47%	19%	0%
Cambodia	17	24%	53%	0%	24%	0%	0%
Cameroon	15	20%	33%	20%	20%	7%	0%
Chile	138	4%	14%	12%	46%	24%	0%
China	1,787	1%	3%	26%	52%	17%	1%
Colombia	328	8%	23%	11%	33%	24%	0%
Costa Rica	32	6%	16%	9%	56%	13%	0%
Cote d'Ivoire	7	0%	43%	14%	29%	14%	0%
Czech Republic	136	7%	15%	6%	35%	38%	0%
Denmark	102	4%	3%	19%	37%	13%	25%
Ecuador	7	0%	0%	0%	86%	0%	14%
Egypt	1,062	3%	33%	3%	11%	2%	49%
Eritrea	5	0%	60%	40%	0%	0%	0%
Estonia	10	10%	30%	0%	30%	30%	0%
Ethiopia	7	0%	14%	29%	43%	14%	0%
France	1,267	5%	16%	9%	41%	27%	0%
Georgia	47	11%	13%	6%	49%	21%	0%
Ghana	7	0%	43%	43%	14%	0%	0%
Greece	179	3%	6%	5%	41%	44%	0%
Guatemala	21	0%	38%	48%	0%	14%	0%
Honduras	27	7%	26%	11%	41%	4%	11%
Hong Kong (China)	23	4%	22%	13%	30%	30%	0%
Hungary	222	2%	5%	6%	44%	43%	0%

	Hemophilia B	0–4	5–13	14–18	19–44	45+	Age Not Known
India	2,127	2%	13%	13%	42%	9%	21%
Iran	1,071	4%	11%	9%	58%	18%	0%
Iraq	330	18%	36%	22%	17%	7%	0%
Ireland	238	7%	16%	8%	41%	28%	0%
Jamaica	4	0%	0%	25%	50%	25%	0%
Kenya	116	15%	22%	30%	25%	7%	2%
Korea, Republic of	409	5%	18%	12%	44%	21%	0%
Kyrgyzstan	27	0%	26%	0%	74%	0%	0%
Latvia	24	0%	21%	0%	63%	17%	0%
Lebanon	43	5%	19%	16%	49%	12%	0%
Malaysia	196	37%	26%	4%	16%	2%	15%
Maldives	3	67%	0%	33%	0%	0%	0%
Mauritania	9	0%	44%	22%	22%	0%	11%
Mauritius	9	0%	11%	33%	44%	11%	0%
Moldova	21	0%	5%	24%	19%	52%	0%
Mongolia	23	30%	17%	26%	22%	4%	0%
Montenegro	4	0%	0%	50%	25%	25%	0%
Nepal	75	20%	20%	33%	16%	11%	0%
New Zealand	80	3%	11%	1%	39%	36%	10%
Nigeria	4	25%	25%	0%	25%	0%	25%
Pakistan	123	11%	20%	15%	44%	5%	6%
Palestine	40	0%	43%	13%	35%	10%	0%
Peru	125	1%	25%	14%	42%	9%	9%
Philippines	173	3%	17%	11%	45%	10%	14%
Poland	419	2%	9%	4%	51%	33%	1%
Portugal	112	1%	9%	6%	39%	37%	8%
Qatar	3	0%	0%	100%	0%	0%	0%
Senegal	18	17%	39%	22%	6%	6%	11%
Serbia	81	6%	19%	11%	41%	23%	0%
Singapore	44	5%	20%	7%	50%	18%	0%
Slovenia	28	0%	7%	0%	39%	36%	18%
South Africa	362	8%	19%	9%	41%	22%	1%
Sudan	150	18%	44%	13%	23%	1%	0%
Sweden	208	2%	6%	6%	22%	27%	38%

	Hemophilia B	0–4	5–13	14–18	19–44	45+	Age Not Known
Syria	69	3%	33%	25%	35%	1%	3%
Tanzania	10	20%	20%	30%	0%	0%	30%
Thailand	57	9%	21%	32%	32%	7%	0%
Togo	5	0%	60%	0%	40%	0%	0%
Uganda	15	13%	40%	20%	27%	0%	0%
United Arab Emirates	15	33%	40%	27%	0%	0%	0%
United Kingdom	1,450	7%	11%	7%	41%	34%	0%
United States	4,421	9%	22%	12%	35%	22%	0%
Uzbekistan	136	4%	20%	14%	58%	4%	0%
Venezuela	556	2%	13%	7%	39%	20%	19%
Vietnam	472	7%	18%	11%	50%	10%	4%
Zimbabwe	13	15%	8%	8%	46%	8%	15%

Table 12. Age distribution: Hemophilia Type Unknown

(14 countries reported age data.)

	Hemophilia Type Unknown	0–4	5–13	14–18	19–44	45+	Age Not Known
Bangladesh	6	0%	0%	100%	0%	0%	0%
Belgium	7	0%	0%	0%	29%	57%	14%
Ethiopia	125	18%	31%	22%	29%	0%	0%
Ghana	50	30%	34%	20%	10%	0%	6%
Hong Kong (China)	7	0%	14%	0%	86%	0%	0%
India	711	1%	5%	6%	21%	5%	62%
Mauritius	3	0%	0%	33%	0%	0%	67%
Nigeria	81	14%	40%	19%	28%	0%	0%
Palestine	73	5%	60%	15%	18%	3%	0%
Peru	50	2%	6%	12%	74%	22%	0%
Philippines	337	4%	15%	44%	5%	5%	27%
Portugal	52	0%	0%	8%	21%	29%	42%
Tanzania	18	11%	44%	17%	6%	0%	22%
Togo	6	67%	17%	0%	0%	17%	0%

Table 13. Age distribution: VWD

(61 countries reported age data.)

	VWD	0–4	5–13	14–18	19–44	45+	Age Not Known
Argentina	404	0%	2%	2%	48%	33%	14%
Australia	2,012	2%	11%	7%	44%	36%	0%
Bangladesh	2	50%	0%	0%	50%	0%	0%
Belarus	192	0%	5%	5%	66%	22%	2%
Belgium	1,810	1%	17%	9%	39%	33%	1%
Brazil	7,223	1%	11%	11%	52%	26%	0%
Cambodia	2	50%	50%	0%	0%	0%	0%
Cameroon	10	0%	20%	10%	60%	10%	0%
China	64	3%	20%	9%	56%	11%	0%
Colombia	1,143	2%	19%	12%	17%	51%	0%
Cote d'Ivoire	3	0%	0%	0%	100%	0%	0%
Czech Republic	810	1%	8%	5%	47%	39%	0%
Ecuador	44	0%	0%	11%	61%	25%	2%
Egypt	528	2%	38%	2%	10%	1%	46%
Estonia	92	2%	24%	12%	41%	11%	10%
Ethiopia	17	0%	6%	41%	53%	0%	0%
France	1,865	2%	13%	10%	41%	34%	0%
Georgia	32	3%	22%	9%	38%	28%	0%
Ghana	7	29%	0%	43%	29%	0%	0%
Greece	1,078	1%	15%	9%	49%	25%	0%
Guatemala	21	0%	10%	43%	48%	0%	0%
Honduras	9	0%	0%	33%	22%	0%	44%
Hong Kong (China)	2	0%	0%	0%	0%	100%	0%
Hungary	1,430	1%	7%	6%	44%	42%	0%
India	483	1%	14%	13%	44%	7%	21%
Iran	1,438	3%	19%	10%	55%	14%	0%
Iraq	304	17%	30%	39%	11%	3%	0%
Ireland	1,273	6%	17%	7%	48%	22%	0%
Kenya	42	14%	31%	24%	17%	5%	10%
Korea, Republic of	116	0%	15%	13%	55%	17%	0%

	VWD	0–4	5–13	14–18	19–44	45+	Age Not Known
Kyrgyzstan	9	0%	67%	0%	33%	0%	0%
Latvia	120	0%	0%	2%	58%	37%	3%
Lebanon	107	2%	13%	20%	50%	13%	3%
Malaysia	614	12%	26%	9%	36%	5%	13%
Mauritania	2	0%	0%	0%	100%	0%	0%
Moldova	6	0%	0%	50%	33%	17%	0%
Mongolia	13	0%	46%	0%	38%	15%	0%
Montenegro	3	0%	0%	67%	33%	0%	0%
New Zealand	224	1%	7%	8%	35%	25%	23%
Pakistan	172	5%	28%	15%	42%	2%	8%
Palestine	35	6%	26%	14%	51%	3%	0%
Peru	171	1%	11%	8%	35%	32%	12%
Philippines	32	0%	0%	9%	47%	0%	44%
Poland	1,715	2%	16%	9%	48%	24%	1%
Portugal	51	2%	4%	4%	37%	49%	4%
Qatar	30	10%	17%	57%	17%	0%	0%
Senegal	7	29%	43%	29%	0%	0%	0%
Serbia	279	1%	8%	8%	54%	29%	0%
Slovenia	184	1%	8%	10%	53%	29%	0%
South Africa	630	1%	8%	8%	45%	34%	4%
Sudan	238	22%	39%	14%	21%	4%	0%
Suriname	5	0%	0%	20%	80%	0%	0%
Sweden	1,512	0%	2%	2%	17%	18%	62%
Syria	70	7%	33%	11%	43%	6%	0%
Uganda	3	0%	100%	0%	0%	0%	0%
United Arab Emirates	40	25%	23%	28%	25%	0%	0%
United Kingdom	10,586	3%	11%	7%	42%	38%	0%
United States	13,845	7%	29%	24%	28%	13%	0%
Uzbekistan	91	5%	10%	5%	65%	3%	11%
Venezuela	933	1%	14%	10%	41%	17%	18%
Vietnam	75	0%	21%	11%	51%	12%	5%

Table 14. HIV and HCV infection

(People currently living with HIV or HCV. 51 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.

Data on HIV and HCV are based on a small number of countries and do not reflect the true global burden of these infections in the bleeding disorders community.

	Total number of people living with HIV			Total number of people infected with hepatitis C*			Total number of people with currently active hepatitis C**		
	Hemophilia	VWD	Other bleeding disorders	Hemophilia	VWD*	Other bleeding disorders	Hemophilia	VWD	Other bleeding disorders
Algeria	1	0	0	31	5	0	9	0	
Argentina	58	0	0	614	21	0			
Austria	49			204					
Colombia	12	0	0	280	30	0	120	20	0
Costa Rica	12	12		50	0	0	15	0	0
Cote d'Ivoire	1	0	0	1	0	0	0	0	0
Czech Republic	3	0	0	210	2	0	62	1	0
Denmark				25					
Dominican Republic	0	0	0	20					
Estonia	0	0	0	28	1				
France	450	14	3	1730	155	43	109	8	2
Georgia				144					
Germany	370			2000					
Greece	58	1	0	327	23	9	187	13	2
Hungary	10								
India	149								
Indonesia	1			57					
Iran	26			319					
Iraq	0	0	0	300	62	5	300	62	5
Ireland	31	0	0	133	7	7	10	0	0
Jamaica	1								
Japan	719	7	3	1820	131	70	1372	107	56
Kenya	23	2	0						

	Total number of people living with HIV			Total number of people infected with hepatitis C*			Total number of people with currently active hepatitis C**		
	Hemophilia	VWD	Other bleeding disorders	Hemophilia	VWD*	Other bleeding disorders	Hemophilia	VWD	Other bleeding disorders
Korea, Republic of	18			550			92		
Kyrgyzstan	0	0	0	21	0	0	21	0	0
Malaysia	1	0	0						
Mauritius	0	0	0	6	0	0	6	0	0
Moldova	0	0		2					
Montenegro				3	0	0	2	0	0
Nepal	1			7					
New Zealand	6	0		39	2		35	2	
Pakistan	9	1	1	150	34	10	150	34	10
Poland	7	0	0						
Serbia	8	2	0	121	10	0			
Singapore				65					
Slovenia	7	0	0	78	6	3	8	0	0
South Africa	71	3	0	217	4	2	19	4	2
Sudan	2			40					
Sweden	35	0	0						
Syria	0	0	0	61	6	0			
Thailand	11	0	0	60	0	0	0	0	0
Togo	1	0	0						
Uganda				1					
United Arab Emirates	0	0	0	3	0	0	0	0	0
United Kingdom	288	4		728	73				
United States	1274	38	25	4137	263	111			
Uzbekistan	8			112	8				
Venezuela	85	9		320	24				
Vietnam	4			11	0	0	289	9	0
Zambia	1	0	0	0	0	0	0	0	0
Zimbabwe	2								
Total	**3,813**	**93**	**32**	**15,025**	**867**	**260**	**2,806**	**260**	**77**

** Hepatitis C antibody positive at any time*

*** Still PCR positive: patients who have not cleared the virus spontaneously or after treatment*

Table 15. Percentage of patients on prophylaxis

(67 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.

	Percent under 18 on prophylaxis	Precise or estimate	Percent over 18 on prophylaxis	Precise or estimate
Algeria	90%	Estimate	40%	Estimate
Argentina	75%	Estimate	5%	Estimate
Australia	83%	Estimate	54%	Estimate
Austria	91%	Precise	63%	Precise
Azerbaijan	20%	Estimate		
Belarus			8%	Precise
Belgium	90%	Estimate	75%	Estimate
Belize	0%	Precise	0%	Precise
Brazil	65%	Estimate	89%	Estimate
Cameroon	0%	Precise	0%	Precise
Chile	100%	Estimate		
China	3%	Estimate	1%	Estimate
Colombia	95%	Precise	65%	Estimate
Costa Rica	20%	Precise	10%	Precise
Cote d'Ivoire	1%	Precise	0%	Precise
Czech Republic	92%	Precise	55%	Precise
Denmark	100%	Precise	40%	Estimate
Dominican Republic	6%	Estimate		
Ecuador			5%	Precise
Eritrea	0%	Precise	0%	Precise
Estonia	100%	Precise	28%	Precise
France	90%	Estimate	40%	Estimate
Germany	100%	Estimate	55%	Estimate
Greece	84%	Precise	30%	Estimate
Honduras	0%	Estimate	0%	Estimate
Hungary	100%	Precise		
Indonesia	5%	Estimate	5%	Estimate
Iran	20%	Precise	0%	Precise
Iraq	100%	Precise	10%	Estimate
Ireland	92%	Estimate	63%	Estimate
Jamaica			0%	Precise

	Percent under 18 on prophylaxis	Precise or estimate	Percent over 18 on prophylaxis	Precise or estimate
Japan	95%	Estimate	70%	Estimate
Kenya	2%	Precise	0%	Precise
Korea, Republic of	54%	Estimate	9%	Estimate
Kyrgyzstan	0%	Precise	0%	Precise
Latvia	100%	Estimate	48%	Precise
Lebanon	23%	Precise	3%	Precise
Lithuania	100%	Precise	25%	Estimate
Macedonia	75%	Precise	1%	Precise
Mauritania	0%	Estimate	1%	Estimate
Mauritius	90%	Estimate	45%	Estimate
Moldova	0%	Precise	0%	Precise
Montenegro	90%	Precise	40%	Precise
Netherlands	100%	Estimate	100%	Estimate
Nigeria	12%	Precise		
Pakistan	1%	Estimate	0%	Estimate
Peru	50%	Estimate	25%	Estimate
Philippines	1%	Estimate	1%	Estimate
Poland	75%	Estimate	50%	Estimate
Qatar	80%	Precise	80%	Precise
Russia	40%	Estimate	20%	Estimate
Senegal	11%	Estimate	0%	Precise
Serbia	90%	Precise	34%	Precise
Singapore	13%	Estimate	16%	Estimate
Slovenia	77%	Precise	64%	Precise
South Africa	30%	Estimate	10%	Estimate
Suriname	1%	Precise	0%	Precise
Syria	0%	Precise	0%	Precise
Thailand	10%	Estimate	5%	Estimate
Uganda	3%	Precise		
Ukraine	0%	Precise	0%	Precise
United Arab Emirates	100%	Precise	100%	Precise
United Kingdom	95%	Estimate	70%	Estimate
United States	87%	Estimate	71%	Estimate
Uzbekistan	0%	Precise	0%	Precise
Venezuela	30%	Estimate	20%	Estimate
Zimbabwe	5%	Estimate	5%	Estimate

Table 16. Reported Use of Factor Concentrates in 2015: Factor VIII

(81 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 based on an estimate or from one region or hospital only. Some countries report the amount of factor concentrate consumed in the year 2015 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 2015.

	Factor VIII Total UI	Factor VIII Plasma Derived	Factor VIII Recombinant	Factor VIII Humanitarian Aid	Factor VIII Per Capita	Factor VIII Per Capita Without Humanitarian Aid	Total Percent Plasma Derived	Total Percent Recombinant
Algeria	75,394,207	47,542,976	27,851,231	No data	1.901	1.901	63	37
Argentina	169,627,500	113,305,000	51,510,000	4,812,500	3.907	3.796	69	31
Australia	146,601,750	8,486,750	138,115,000	0	6.165	6.165	6	94
Azerbaijan	5,000	No data	No data	5,000	0.001			
Bangladesh	835,786	No data	No data	835,786	0.005			
Belarus	30,000,000	No data	No data	No data	3.154	3.154		
Belize	208,765	No data	No data	208,765	0.581			
Brazil	611,910,000	175,102,500	436,807,500	0	2.944	2.944	29	71
Cambodia	252,200	No data	No data	252,200	0.016			
Cameroon	511,000	No data	No data	511,000	0.022			
Chile	53,000,000	53,000,000	No data	0	2.953	2.953	100	
Colombia	251,281,000	134,518,000	116,763,000	0	5.21	5.21	54	46
Cote d'Ivoire	320,000	0	0	320,000	0.014	0	0	0
Czech Republic	51,064,250	27,295,500	23,768,750	0	4.84	4.84	53	47
Denmark	81,000,000	1,000,000	80,000,000	0	14.271	14.271	1	99
Dominican Republic	1,673,500	461,000	0	1,212,500	0.159	0.044	100	0
Ecuador	23,291	No data	No data	15,340	0.001	0		
Egypt	32,711,750	31,946,000	660,000	105,750	0.357	0.356	98	2
Eritrea	419,721	No data	No data	419,721	0.072			

	Factor VIII Total UI	Factor VIII Plasma Derived	Factor VIII Recombinant	Factor VIII Humanitarian Aid	Factor VIII Per Capita	Factor VIII Per Capita Without Humanitarian Aid	Total Percent Plasma Derived	Total Percent Recombinant
Estonia	4,315,500	3,961,500	354,000	No data	3.289	3.289	92	8
Ethiopia	551,600	0	0	551,600	0.006	0	0	0
Georgia	7,206,302	7,200,000	No data	6,302	1.959	1.957	100	
Germany	594,595,929	231,585,283	363,010,646	0	7.303	7.303	39	61
Ghana	401,833	No data	No data	401,833	0.015			
Greece	40,560,200	6,561,000	33,999,200	0	3.747	3.747	16	84
Guatemala	169,031	No data	No data	169,031	0.01			
Honduras	9,034,140	No data	0	771,640	1.119	1.023		0
Hungary	109,000,000	71,000,000	38,000,000	No data	11.072	11.072	65	35
India	88,417,894	68,000,354	17,000,000	3,417,540	0.067	0.065	80	20
Indonesia	888,700	No data	No data	888,700	0.003			
Iran	180,000,000	No data	No data	0	2.275	2.275		
Iraq	50,000,000	0	50,000,000	0	1.373	1.373	0	100
Ireland	41,773,350	4,684,400	37,088,950	0	9.002	9.002	11	89
Jamaica	714,930	No data	No data	714,930	0.262			
Japan	732,200,000	84,900,000	647,300,000	0	5.767	5.767	12	88
Kenya	2,632,500	0	0	2,632,500	0.057	0	0	0
Korea, Republic of	198,118,000	39,299,000	158,819,000	0	3.914	3.914	20	80
Kyrgyzstan	1,190,510	33,500	277,750	879,260	0.2	0.052	11	89
Latvia	4,194,250	2,702,000	1,492,250	0	2.12	2.12	64	36
Lebanon	301,740	No data	No data	301,740	0.052			
Lithuania	15,011,750	8,770,500	6,241,250	No data	5.158	5.158	58	42
Macedonia	6,000,000	6,000,000	0	0	2.887	2.887	100	0
Malaysia	13,197,500	12,777,500	420,000	No data	0.435	0.435	97	3
Maldives	200,000	0	0	200,000	0.489	0	0	0
Mauritania	414,500	No data	No data	94,500	0.102	0.079		
Mauritius	2,062,500	2,062,500	0	0	1.634	1.634	100	0
Moldova	589,840	No data	0	189,840	0.166	0.113		0
Mongolia	2,334,630	No data	1,561,200	773,430	0.789	0.528		100
Montenegro	1,297,500	1,297,500	0	0	2.085	2.085	100	0
Nepal	549,600	No data	No data	549,600	0.019			

	Factor VIII Total UI	Factor VIII Plasma Derived	Factor VIII Recombinant	Factor VIII Humanitarian Aid	Factor VIII Per Capita	Factor VIII Per Capita Without Humanitarian Aid	Total Percent Plasma Derived	Total Percent Recombinant
New Zealand	27,067,250	4,142,000	22,925,250	No data	5.89	5.89	15	85
Nigeria	2,786,319	0	0	2,786,319	0.015	0	0	0
Pakistan	3,136,610	208,600	1,221,950	1,706,060	0.017	0.008	15	85
Palestine	4,224,000	No data	No data	No data	0.955	0.955		
Philippines	4,201,000	2,000,000	0	2,201,000	0.042	0.02	100	0
Poland	218,596,350	212,609,500	5,986,850	0	5.753	5.753	97	3
Portugal	52,685,750	19,335,000	33,350,750	No data	5.091	5.091	37	63
Qatar	250,000	0	250,000	0	0.112	0.112	0	100
Russia	838,873,966	702,959,966	135,914,000	0	5.822	5.822	84	16
Senegal	1,319,750	No data	No data	1,319,750	0.087			
Serbia	17,032,850	13,482,600	3,550,250	0	2.4	2.4	79	21
Singapore	2,909,500	2,767,750	141,750	No data	0.526	0.526	95	5
Slovenia	15,972,150	3,851,000	12,121,150	0	7.739	7.739	24	76
South Africa	52,849,850	51,289,100	1,560,750	0	0.962	0.962	97	3
Sri Lanka	1,474,000	No data	No data	1,474,000	0.07			
Sudan	5,675,000	4,714,000	No data	961,000	0.141	0.117	100	
Suriname	74,000	2,000	30,000	42,000	0.136	0.059	6	94
Sweden	87,875,000	No data	No data	No data	8.968	8.968		
Syria	905,750	0	0	905,750	0.049	0	0	0
Tanzania	339,000	No data	No data	339,000	0.006			
Thailand	628,760	0	0	628,760	0.009	0	0	0
Togo	117,500	No data	No data	117,500	0.016			
Uganda	153,350	No data	No data	153,350	0.004			
Ukraine	24,351,892	No data	No data	310,500	0.539	0.532		
United Kingdom	549,161,172	45,825,480	503,335,692	0	8.431	8.431	8	92
United States	2,652,840,000	343,440,000	2,309,400,000	No data	8.254	8.254	13	87
Uzbekistan	2,456,090	No data	No data	2,456,090	0.078			
Venezuela	57,854,200	5,597,100	48,230,000	4,027,100	1.86	1.73	10	90
Vietnam	12,956,200	12,956,200	0	0	0.141	0.141	100	0
Zambia	346,000	No data	No data	346,000	0.021			
Zimbabwe	1,200,000	No data	No data	1,200,000	0.077			
Total	**8,255,077,208**	**2,568,673,059**	**5,309,058,119**	**42,215,187**			**31%**	**64%**

Table 17. Reported Use of Factor Concentrates in 2015: Factor IX

(68 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 based on an estimate or from one region or hospital only. Some countries report the amount of factor concentrate consumed in the year 2015 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 2015.

	Factor IX Total UI	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
Algeria	8,397,995	8,397,995	No data	No data	0.212	0.212	100	
Argentina	14,662,000	11,687,000	2,975,000	0	0.338	0.338	80	20
Australia	26,442,100	2,305,000	24,137,100	0	1.112	1.112	9	91
Azerbaijan	5,220	No data	No data	5,220	0.001			
Bangladesh	92,000	No data	No data	92,000	0.001			
Belize	185,960	No data	No data	185,960	0.518			
Brazil	103,356,950	103,356,950	0	0	0.497	0.497	100	0
Cambodia	57,420	No data	No data	57,420	0.004			
Cameroon	20,000	No data	No data	20,000	0.001			
Chile	8,000,000	8,000,000	No data	0	0.446	0.446	100	
Colombia	41,622,000	28,633,000	12,989,000	0	0.863	0.863	69	31
Costa Rica	1,827	No data	0	1,827	0			
Cote d'Ivoire	26,100	0	0	26,100	0.001	0	0	0
Czech Republic	6,816,005	6,460,496	355,509	0	0.646	0.646	95	5
Denmark	18,000,000	0	18,000,000	0	3.171	3.171	0	100
Dominican Republic	180,000	30,000	0	150,000	0.017	0.003	100	0
Ecuador	500	No data	No data	0	0	0		
Estonia	476,700	476,700	0	No data	0.363	0.363	100	0
Ethiopia	20,880	No data	No data	20,880	0			

	Factor IX Total UI	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
Georgia	805,220	800,000	No data	5,220	0.219	0.217	100	
Germany	68,625,908	43,091,300	25,534,608	0	0.843	0.843	63	37
Ghana	60,000	No data	No data	60,000	0.002			
Greece	5,190,100	422,000	4,768,100	0	0.48	0.48	8	92
Honduras	40,000	No data	No data	40,000	0.005			
Hungary	6,500,000	6,500,000	0	No data	0.66	0.66	100	0
India	2,000,000	2,000,000	No data	0	0.002	0.002	100	
Iran	25,000,000	25,000,000	0	0	0.316	0.316	100	0
Iraq	12,000,000	0	12,000,000	0	0.329	0.329	0	100
Ireland	13,182,100	450,000	12,732,100	0	2.841	2.841	3	97
Japan	128,700,000	57,200,000	71,500,000	0	1.014	1.014	44	56
Kenya	550,000	0	0	550,000	0.012	0	0	0
Korea, Republic of	43,457,000	2,494,000	40,963,000	0	0.859	0.859	6	94
Kyrgyzstan	123,650	13,000	6,250	104,400	0.021	0.003	68	32
Latvia	603,000	603,000	0	0	0.305	0.305	100	0
Lebanon	58,050	No data	No data	58,050	0.01			
Lithuania	2,805,700	2,805,700	0	No data	0.964	0.964	100	0
Macedonia	1,000,000	1,000,000	0	0	0.481	0.481	100	0
Malaysia	3,821,500	3,598,000	223,500	No data	0.126	0.126	94	6
Mauritius	227,500	227,500	0	0	0.18	0.18	100	0
Moldova	894,760	No data	0	594,760	0.252	0.084		0
Mongolia	313,500	No data	313,500	No data	0.106	0.106		100
Montenegro	100,000	100,000	0	0	0.161	0.161	100	0
Nepal	133,143	No data	No data	133,143	0.005			
New Zealand	3,368,500	1,501,000	1,867,500	No data	0.733	0.733	45	55
Nigeria	375,000	No data	No data	375,000	0.002			
Pakistan	1,150,000	300,000	300,000	550,000	0.006	0.003	50	50
Palestine	960,000	No data	No data	No data	0.217	0.217		
Philippines	857,400	0	0	857,400	0.009	0	0	0
Poland	33,652,200	32,402,200	1,250,000	0	0.886	0.886	96	4

	Factor IX Total UI	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
Portugal	8,148,000	5,275,000	2,873,000	No data	0.787	0.787	65	35
Qatar	35,000	0	35,000	0	0.016	0.016	0	100
Russia	99,140,361	99,140,361	0	0	0.688	0.688	100	0
Senegal	250,000	No data	No data	250,000	0.017			
Serbia	2,444,500	2,444,500	0	0	0.344	0.344	100	0
Singapore	547,000	547,000	0	No data	0.099	0.099	100	0
Slovenia	956,000	578,000	378,000	0	0.463	0.463	60	40
South Africa	6,997,500	6,997,500	No data	0	0.127	0.127	100	
Sri Lanka	300,000	No data	No data	300,000	0.014			
Sudan	888,000	No data	No data	No data	0.022	0.022		
Sweden	17,576,000	No data	No data	No data	1.794	1.794		
Tanzania	13,050	No data	No data	13,050	0			
Ukraine	4,491,340	No data	No data	0	0.099	0.099		
United Kingdom	91,982,767	9,473,960	82,508,807	0	1.412	1.412	10	90
United States	492,300,000	80,100,000	412,200,000	No data	1.532	1.532	16	84
Uzbekistan	300,000	No data	No data	300,000	0.01			
Venezuela	5,500,000	5,500,000	No data	No data	0.177	0.177	100	
Vietnam	1,510,850	1,510,850	0	0	0.016	0.016	100	0
Zimbabwe	100,000	No data	No data	100,000	0.006			
Total	**1,318,398,256**	**561,422,012**	**727,909,974**	**4,850,430**			**43%**	**55%**

Annual Global Survey **2015**

A. National Hemophilia Organization

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

Please [Click Here] **to validate Organization contact information**

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):
What percentage of the patient population in your country are you reporting on? Please provide your best estimate	Percentage ☐ Not Known

Please [Click Here] **to validate Data source**

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 ☐

Please [Click Here] **to validate number of patients**

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 ☐

Please Click Here **to validate Age section**

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
A woman who has less than 40 percent of the normal level of clotting factor would be considered a person with hemophilia. A woman with more than 40% FVIII is considered a carrier and should not be included in this report.

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

Please Click Here **to validate Gender section**

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 gender and 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 percent of the normal level of clotting factor would be considered a person with hemophilia. A woman with more than 40% FVIII is considered a carrier and should not be included in this report.

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 2015**	**No Data**
Hemophilia A			☐
Hemophilia B			☐

Please [Click Here] **to validate classification, severity and inhibitors**

11. Availability and usage of products to treat hemophilia

Treatment product	**Product is available**	**Product is used**	**Number of patients treated with product indicated**	**No data**
Plasma	☐	☐		☐
Cryoprecipitate	☐	☐		☐
Plasma-derived concentrate	☐	☐		☐
Recombinant concentrate (excluding prolonged half-life)	☐	☐		☐
Recombinant concentrate (prolonged half-life)	☐	☐		☐
DDAVP (Desmopressin)	☐	☐		☐

PLEASE NOTE: We are asking for the number of patients treated, not a percentage. Please provide your best estimate.

12. Availability and usage of products to treat VWD

Treatment product	**Product is available**	**Product is used**	**Number of patients treated with product indicated**	**No data**
Plasma	☐	☐		☐
Cryoprecipitate	☐	☐		☐
Plasma-derived concentrate	☐	☐		☐
DDAVP (Desmopressin)	☐	☐		☐

PLEASE NOTE: We are asking for the number of patients treated, not a percentage. Please provide your best estimate.

13. HIV infection

	Hemophilia A or B, or type unknown	**von Willebrand disease**	**Other hereditary bleeding disorders**
Total number of people living with HIV			
New HIV infections in 2015			

14. Hepatitis C infection

	Hemophilia A or B, or type unknown	**von Willebrand disease**	**Other hereditary bleeding disorders**
Total number of people infected with hepatitis C[1]			
Total number of people with currently active hepatitis C[2]			
New hepatitis C infections in 2015			

[1] Hepatitis C antibody positive at any time

[2] Still PCR positive: patients who have not cleared the virus spontaneously or after treatment

15. Number and cause of deaths of people with bleeding disorders (January 1-December 31, 2015)

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			

Please Click Here **to validate products, HIV, HCV, and cause of death sections**

C. Hemophilia Care System in Your Country

We define as Hemophilia Treatment Centre (HTC) a medical centre providing any level of care (including basic diagnosis and treatment) for inherited bleeding disorders. Please provide the number of all such centres in your country. Please also indicate how many of those centers have **direct access, within the same structure,** to at least the following: hemophilia doctor, nurse, physiotherapist, social worker, and special coagulation laboratory.

16. How many **hemophilia treatment centres** are there in total in your country?	
How many of the **hemophilia treatment centres** you have indicated above have **direct access, within the same structure,** to a hemophilia doctor, nurse, physiotherapist, social worker, and special coagulation laboratory?	
Which percentage of the hemophilia patients in your country has access to a hemophilia treatment centre:	

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 children (under age 18) **with severe hemophilia** are on prophylaxis?		Precise: ☐ Estimate: ☐	Not known ☐
What percentage of adults (over age 18), **with severe hemophilia** are on prophylaxis?		Precise: ☐ Estimate: ☐	Not known ☐
What is the most common dose (IU/kg) of factor administered and frequency?			

Immune tolerance induction (ITI) is the administration of FVIII or FIX concentrate in patients with inhibitors to eradicate the inhibitors. Please indicate the total percentage of patients with inhibitors receiving ITI in your country and the number of patients having received ITI during last year and indicate if what you provided is precise or an estimate.

18. What **percentage** of patients **with inhibitors** are receiving or have ever received immune tolerance induction?		Precise: ☐ Estimate: ☐	Not known ☐
How many patients **with inhibitors** have received immune tolerance induction in the last year?		Precise: ☐ Estimate: ☐	Not known ☐

Please Click Here **to validate Care section**

D. The Cost and Use of Factor Concentrates

19 A. Annual usage of purchased factor concentrates (please do not include humanitarian aid)	**Factor VIII**	**Not known**	**Factor IX**	**Not known**
IN TOTAL how many international units (IU) of factor concentrates were used in your country in 2015 (excluding humanitarian aid)?		☐		☐
How many international units of **plasma-derived** concentrates were used in your country in 2015 (excluding humanitarian aid)?		☐		☐
How many international units of **recombinant** concentrates were used in your country in 2015 (excluding humanitarian aid)?		☐		☐

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

19 B. Annual usage of donated factor concentrates	**Factor VIII**	**Not known**	**Factor IX**	**Not known**
How many international units of **humanitarian aid** (plasma-derived or recombinant) concentrates were used in your country in 2015?		☐		☐

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:

Please Click Here **to validate Factors section**

20. Factor VIII Concentrates used in 2015

(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	Baxalta (Baxter Bioscience)	
☐	Adynovate	Baxalta (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	Baxalta (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	Baxalta (Baxter Bioscience)	
☐	Koate DVI	Talecris	
☐	Kogenate FS = KOGENATE Bayer (in EU)	Bayer	
☐	Monoclate P	CSL Behring	

☐	Novoeight	NovoNordisk	
☐	Nuwiq	Octapharma	
☐	Octanate	Octapharma	
☐	Octanativ-M	Octapharma	
☐	Octavi SD	Octapharma	
☐	Optivate	Bio Products Laboratory	
☐	FVIII by Quimbiotec	Quimbiotec	
☐	Recombinate rAHF	Baxalta (Baxter Bioscience)	
☐	ReFacto AF	Pfizer (Wyeth)	
☐	Replenate	Bio Products Laboratory	
☐	UNC Hemoderivados	Laboratorio de Hemoderivados de Universidad Nacional de Córdoba	
☐	Voncento	CSL Behring	
☐	Wilate	Octapharma	
☐	Xyntha	Pfizer (Wyeth)	
☐	Other:		

PLEASE NOTE: For “Other”, please provide the Brand Name and Manufacturer.

21. Factor IX Concentrates used in 2015

(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	Baxalta (Baxter Bioscience)	
☐	Hemo-B-RAAS	Shanghai RAAS	
☐	Haemonine	Biotest	
☐	Humafactor IX	Kedrion	
☐	Immunine	Baxalta (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:		

PLEASE NOTE: For “Other”, please provide the Brand Name and Manufacturer.

22. Prothrombin Complex Concentrates used in 2015

(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	Baxalta (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	Baxalta (Baxter Bioscience)	
☐	Prothrombinex PXT	CSL Bioplasma	
☐	Prothrombinex- VF	CSL Bioplasma	
☐	Prothromplex-T	Baxalta (Baxter Bioscience)	
☐	Prothroraas	Shanghai RAAS	
☐	UMAN Complex D.I.	Kedrion	
☐	Other:		

PLEASE NOTE: For “Other”, please provide the Brand Name and Manufacturer.

23. Other Products used in 2015

(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	Baxalta (Baxter Bioscience)	
☐	Factor VII	Bio Products	

☐	Factor X P Behring	CSL Behring	
☐	Factor XI	Bio Products	
☐	FEIBA	Baxalta (Baxter Bioscience)	
☐	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 (=Niastase) (activated factor VII)	NovoNordisk	Price per vial: Vial size:
☐	Riastap	CSL Behring	
☐	Tretten rXIII	NovoNordisk	
☐	WILFACTIN (Von Willebrand Factor)	LFB	
☐	Other:		

PLEASE NOTE: For “Other”, please provide the Brand Name and Manufacturer.

Please return to:
Email: globalsurvey@wfh.org
Fax: 514-875-8916
Address: **World Federation of Hemophilia**
1425 René Lévesque Boulevard West, suite 1010
Montréal, Québec, H3G 1T7
Canada

Please provide your feedback on the WFH Annual Global Survey data collection system.

Comments:

Glossary of terms

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.

WFH

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