WORLD FEDERATION OF HEMOPHILIA

WFH

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

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All data are provisional.

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THE WORLD FEDERATION OF HEMOPHILIA IS PROUD TO BE CELEBRATING 20 YEARS OF THE ANNUAL GLOBAL SURVEY

The Report on the Annual Global Survey (AGS) 2018 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. In this 20th anniversary edition, the report provides an international snapshot of the progress in hemophilia patient identification and access to care over time. Over the years this report has given the national member organizations (NMOs) affiliated with World Federation of Hemophilia (WFH), healthcare providers and policy makers an overview of the patterns and trends in hemophilia and its treatment. The annual report offers useful information to support efforts in improving or sustaining the care of people with bleeding disorders, and to assist with advocacy and program planning. The WFH is proud to be celebrating the 20th anniversary of the AGS as it has shown continuous improvement every year, and is appreciative of all the effort and support put forth by the NMOs.

In this 20th anniversary edition, new graphs and tables have been added to show the progress since the WFH started collecting data through the AGS. Supplementary charts and graphs using 2018 data can be found on the website at: **https://www.wfh.org/en/our-work-research-data/annual-global-survey**.

Methodology

In 1998, the WFH began collecting information on hemophilia care throughout the world. This survey, called the WFH AGS, 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 human immunodeficiency virus (HIV) and hepatitis C (HCV). The WFH compiled the first survey report in 1999.

Each year questionnaires are sent to NMOs 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.

Annual Global Survey 2018

The Report on the AGS 2018 includes data on more than 337,000 PWH, VWD and other bleeding disorders in 125 countries. A list of participating countries and the last year they provided data can be found on page 31.

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 population statistics (Table 7) and in the calculation for factor VIII and IX per capita (Table 17 and 18). 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 graphs showing the increase over time in patients identified (Figure A) contain historical data from the AGS. These graphs were was created using aggregate numbers to demonstrate the increase in patients identified over time. If a country did not report the number of identified patients in 2018, data from the latest year they reported is used, on the assumption that the number of patients did not change substantially from one year to the next. For all other tables and graphs, the analysis was done using only data from countries that responded in 2018, with the number of respondents as the denominator.

Comments on data collection

Participation in the AGS 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 PWH 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 2018 only. It includes only those countries where the NMO provided information. Quantities reported were not independently verified except when the WFH has data on humanitarian donations it provided in 2018.

Some countries are not reporting for the whole country and in some cases the numbers reported may be based on an estimate or from one region or certain treatment centres only. The amounts reported may only be factor bought through government and not through other sources. Not all NMOs 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 286,641 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 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 such as laboratory screening or follow up with family members to identify additional patients who do not require treatment.

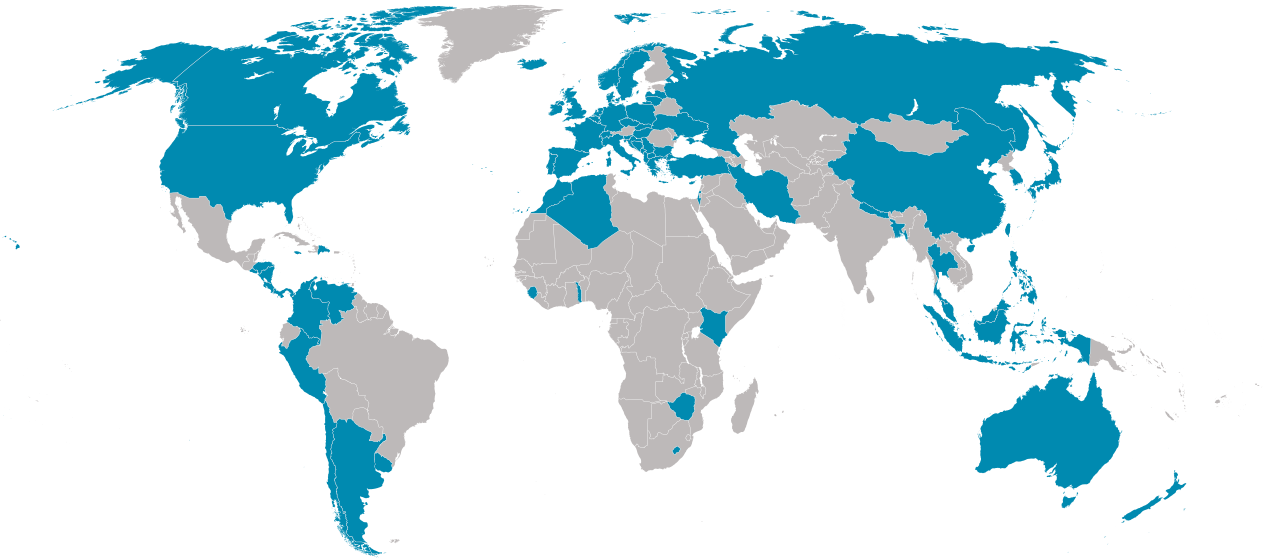
f) Methods of data collection and the state of registries can vary. Maintaining accurate registries can be time consuming and expensive. It is possible that some registries contain patients who have been double-entered or have died. Even wealthy countries with excellent registries have to carefully review their records to avoid over-counting. Countries with large populations are more susceptible to over-counting and it can be 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 HCV is not the same around the world. In some countries infection rates may be lower, while other countries may have had better treatment for infected people with hemophilia.

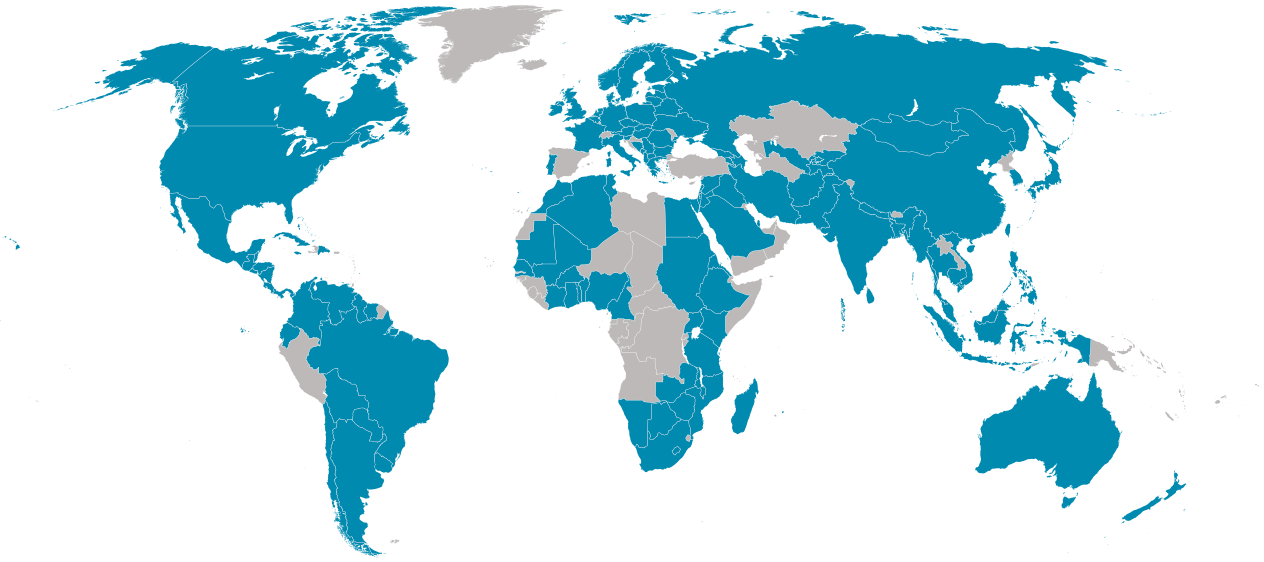
The Report on the AGS is collected under the supervision of the WFH Data & Demographics Committee, including:

COUNTRY REPRESENTATION

Annual Global Survey 1999



Annual Global Survey 2018



Countries included Countries not included

The WFH has a total of 140 national member organizations (NMO). The report on the Annual Global Survey 1999 included data from 65 NMOs. The Report on the Annual Global Survey 2018 includes data from 125 NMOs.

COMPARISON OF KEY NUMBERS FROM THE REPORT ON THE ANNUAL GLOBAL SURVEY (1999-2018)

1999		2018
65	**NUMBER OF COUNTRIES** in this survey	125
	+60 COUNTRIES	
82% (65/79)	**RESPONSE RATE** from WFH National Member Organizations	**89%** (125/140)
78,629	**NUMBER OF PEOPLE IDENTIFIED WITH:**	210,454
24,806	VON WILLEBRAND DISEASE	78,547
7,768	OTHER BLEEDING DISORDERS	48,640

HEMOPHILIA

53,864	HEMOPHILIA A	173,711
11,591	HEMOPHILIA B	34,289
13,174	HEMOPHILIA TYPE UNKNOWN	2,454

▲ 204% INCREASE IN NUMBER OF PEOPLE WITH BLEEDING DISORDERS IDENTIFIED SINCE 1999

REPORT ON THE ANNUAL GLOBAL SURVEY COMPARATIVE SUMMARY DEMOGRAPHICS (1999-2018)

TABLE 1. **Demographics**

	1999	2018
Number of countries in the survey	**65**	**125**
World population covered by countries in this survey report	**3,357,945,164**	**6,990,954,264**
Number of people identified with Hemophilia	**78,629**	**210,454**
Number of people with hemophilia A	**53,864**	**173,711**
Number of people with hemophilia B	**11,591**	**34,289**
Number of people with hemophilia type unknown or type not reported	**13,174**	**2,454**
Number of people identified with VWD	**24,806**	**78,547**
Number of people identified with Other Bleeding Disorders	**7,768**	**48,640**
Total number of people with bleeding disorders identified	**111,203**	**337,641**
Number of people with hemophilia A with clinically identified inhibitors	**2,741***	**6,929**
Number of people with hemophilia B with clinically identified inhibitors	**179***	**394**

*Collection of data on inhibitors started in 2006

FACTOR USAGE SUMMARY

Factor VIII
Usage per capita
0.875 IU
(0.12 – 3.64) Median (IQR)
(111 countries, 88% of world population)

Factor IX
Usage per capita
0.15 IU
(0.02-0.59) Median (IQR)
(105 countries, 87% of the world population)

TABLE 2. **Factor VIII usage 2018**

	FACTOR USAGE	NUMBER OF COUNTRIES REPORTING
Mean (SD) global per capita factor VIII usage	**2.40 IU (3.08)**	**111**
Median global per capita factor VIII usage	**0.875 IU**	**111**
Interquartile range (IQR) global per capita factor VIII usage	**3.52 IU (0.12 to 3.64)**	**111**
Total reported annual global consumption of factor VIII concentrates	**11,093,405,373 IU**	**111**

TABLE 3. **Factor IX usage 2018**

	FACTOR USAGE	NUMBER OF COUNTRIES REPORTING
Mean (SD) global per capita factor IX usage	**0.37 IU (0.50)**	**105**
Median global per capita factor IX usage	**0.15 IU**	**105**
Interquartile range (IQR) global per capita factor IX usage	**0.57 IU (0.02 to 0.59)**	**105**
Total reported annual global consumption of factor IX concentrates	**1,678,135,231 IU**	**105**

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 standard deviation (SD) describes the amount of variation of dispersion from the mean. The interquartile range (IQR) describes the middle 50% of reported numbers and is less likely to be distorted by outliers (extreme values).

TABLE 4. **Factor use in 2002* and 2018**

	2002	2018	NUMBER OF COUNTRIES REPORTING
FACTOR VIII			
Mean (SD) global per capita factor VIII usage	1.57 IU (3.65)	3.91 IU (1.85)	40
Median global per capita factor VIII usage	0.79 IU	2.91 IU	40
Interquartile range (IQR) global per capita factor VIII usage	1.76 IU (0.25 to 2.01)	4.44 IU (1.19 to 5.63)	40
FACTOR IX			
Mean global per capita factor IX usage (Standard deviation)	0.35 IU (0.47)	0.63 IU (0.57)	35
Median global per capita factor IX usage	0.19 IU	0.55 IU	35
Interquartile range (IQR) global per capita factor IX usage	0.36 IU (0.05 to 0.41)	0.64 IU (0.17 to 0.81)	35

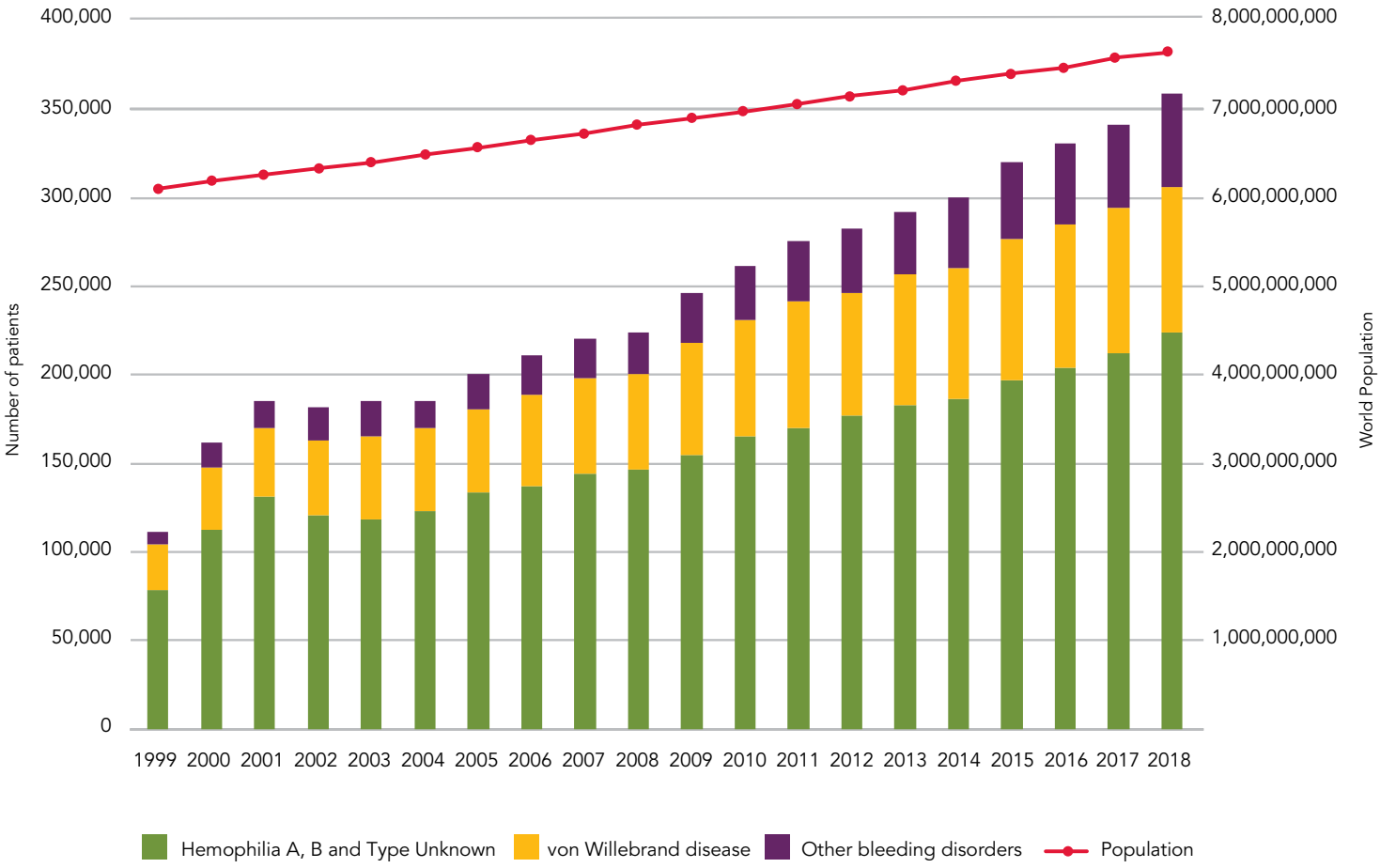
**Collection of factor use data started in 2002*

TABLE 5. **Factor use in 2017 and 2018**

	2017	2018	NUMBER OF COUNTRIES REPORTING
FACTOR VIII			
Mean (SD) global per capita factor VIII usage	2.49 IU (3.11)	2.57 IU (3.28)	90
Median global per capita factor VIII usage	1.09 IU	0.87 IU	90
Interquartile range (IQR) global per capita factor VIII usage	4.26 IU (0.08 to 4.34)	4.20 IU (0.12 to 4.32)	90
FACTOR IX			
Mean global per capita factor IX usage (Standard deviation)	0.38 IU (0.53)	0.40 IU (0.55)	84
Median global per capita factor IX usage	0.17 IU	0.14 IU	84
Interquartile range (IQR) global per capita factor IX usage	0.55 IU (0.01 to 0.56)	0.63 IU (0.02 to 0.65)	84

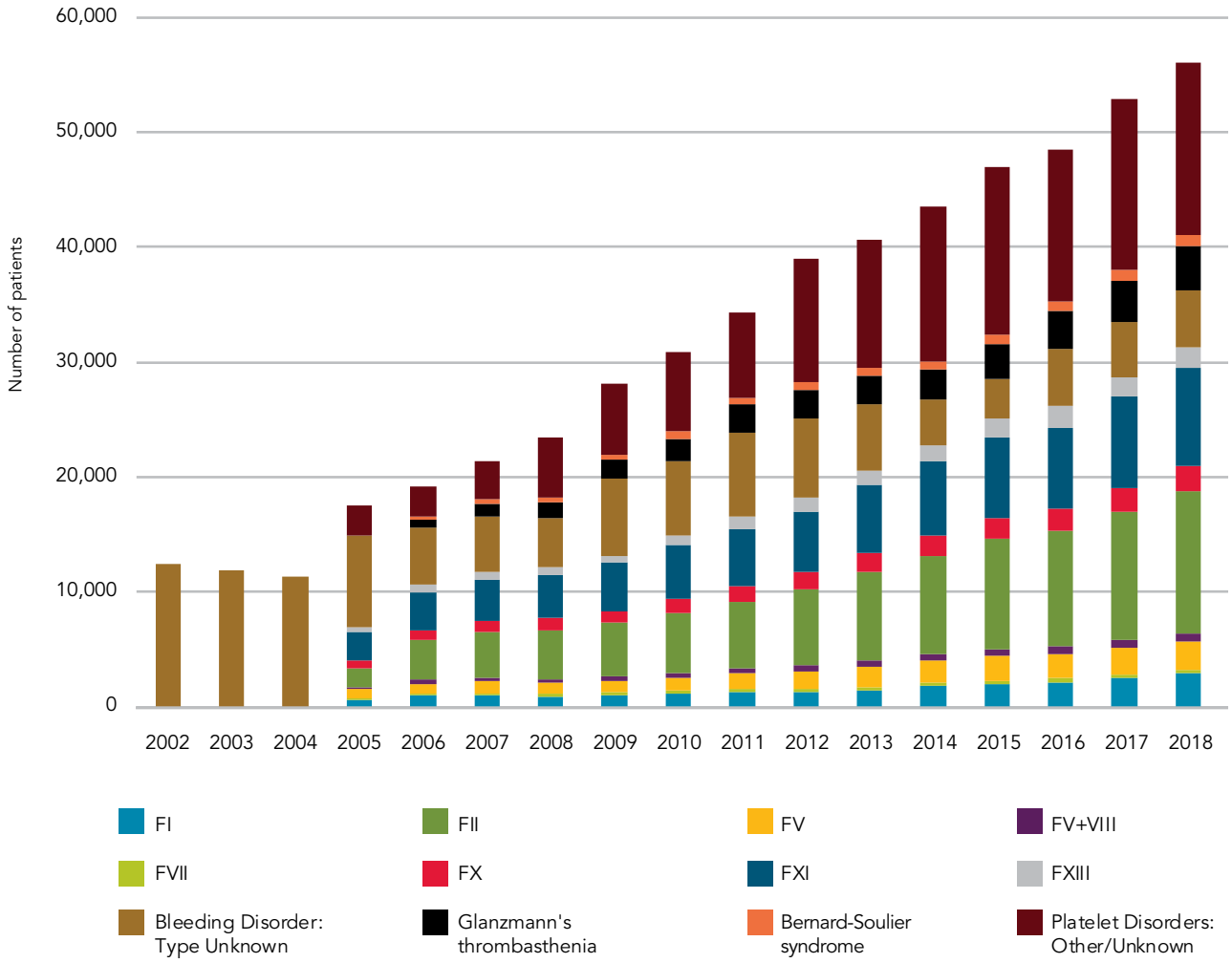
These tables show the mean, median and interquartile range (IQR) of per capita factor usage for the countries that reported in both years indicated. The standard deviation (SD) describes the amount of variation of dispersion from the mean. The interquartile range (IQR) describes the middle 50% of reported numbers and is less likely to be distorted by outliers (extreme values).

FIGURE A1. **Identified patients over time – all bleeding disorders**



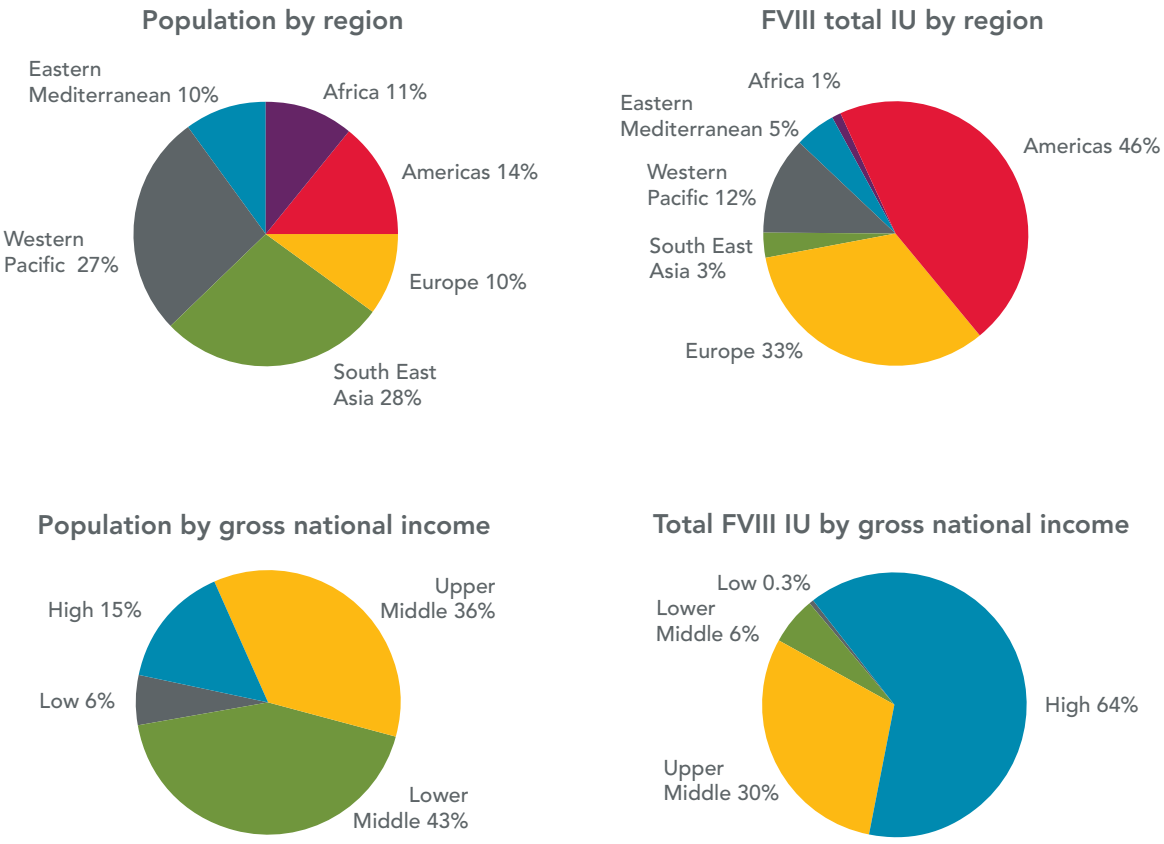
This graph was created using aggregate numbers to demonstrate the increase in patients identified over time. This graph contains historical data from the Annual Global Survey. That is, if a country reported data one year and not the next, the older data were used under the assumption that the number of patients did not change substantially from one year to the next.

FIGURE A2. **Identified patients over time – other rare bleeding disorders**



This graph was created using aggregate numbers to demonstrate the increase in patients identified over time. This graph contains historical data from the Annual Global Survey. That is, if a country reported data one year and not the next, the older data were used under the assumption that the number of patients did not change substantially from one year to the next.

FIGURE B. **Global distribution of factor use**



Economic category based on The World Bank Group 2018 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

FIGURE C1. **Country representation by region**

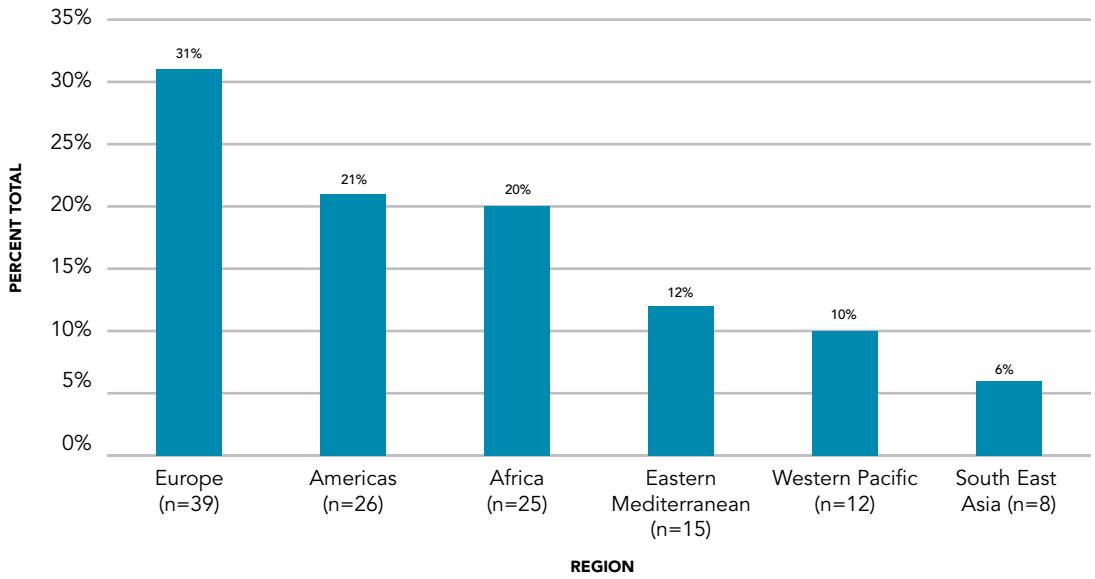
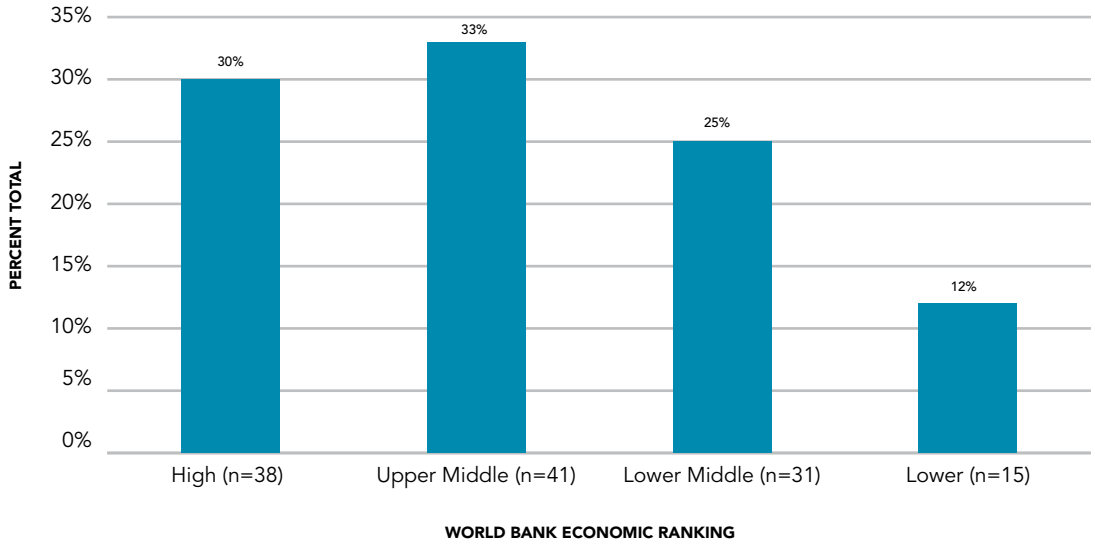


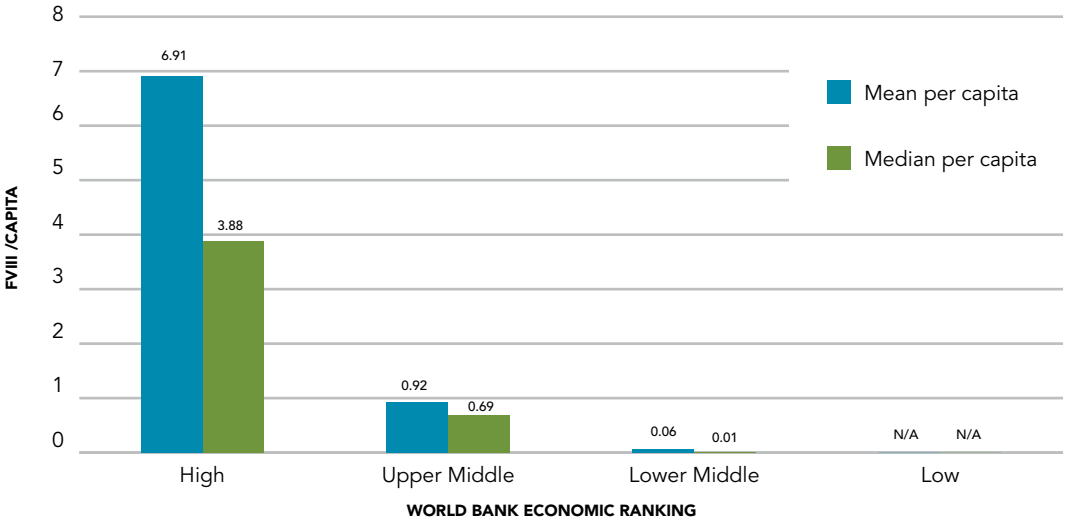
FIGURE C2. **Country representation by gross national income**



Economic category based on The World Bank Group 2018 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

FIGURE D1. **Mean and median global factor VIII per capita 2002**

(Data from 61 countries.)



Economic category based on The World Bank Group 2018 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

Numbers in Figure D1 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. 2002 was the first year factor use data was collected through the AGS. In 2002, there were no low income countries included in the survey. This is reported as N/A in Figure D1.

FIGURE D2. **Mean and median global factor VIII per capita 2018**

(Data from 111 countries.)

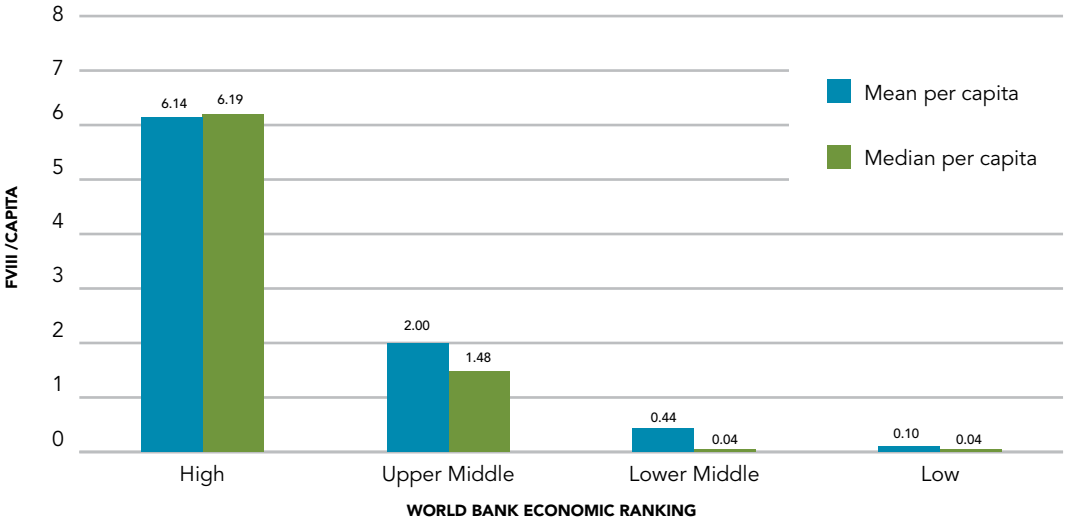


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FIGURE E1. **Mean and median global factor FVIII per patient 2002**

(Data from 59 countries.)

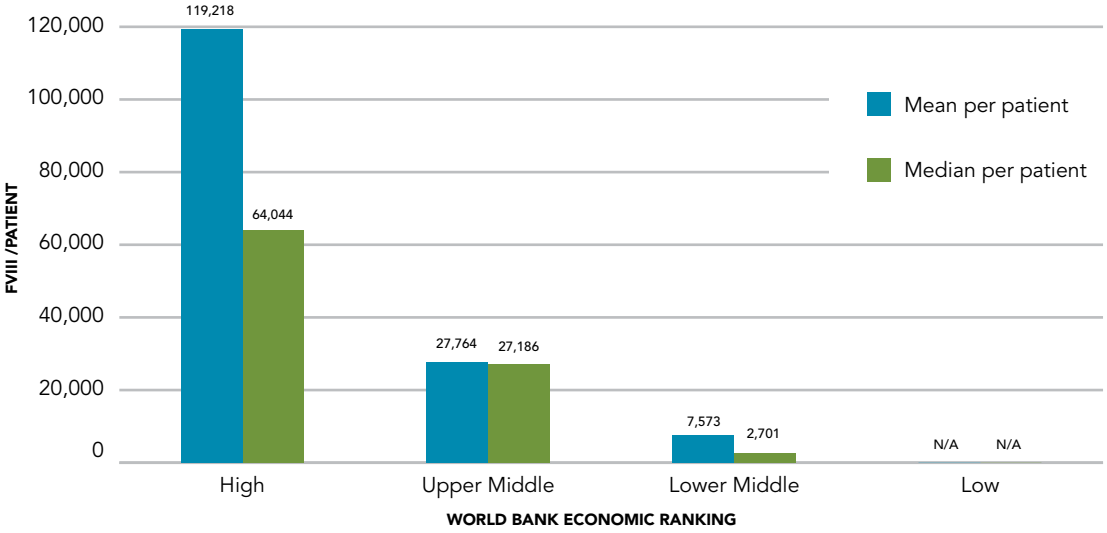

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FIGURE E2. **Mean and median global factor VIII per patient 2018**

(Data from 111 countries.)

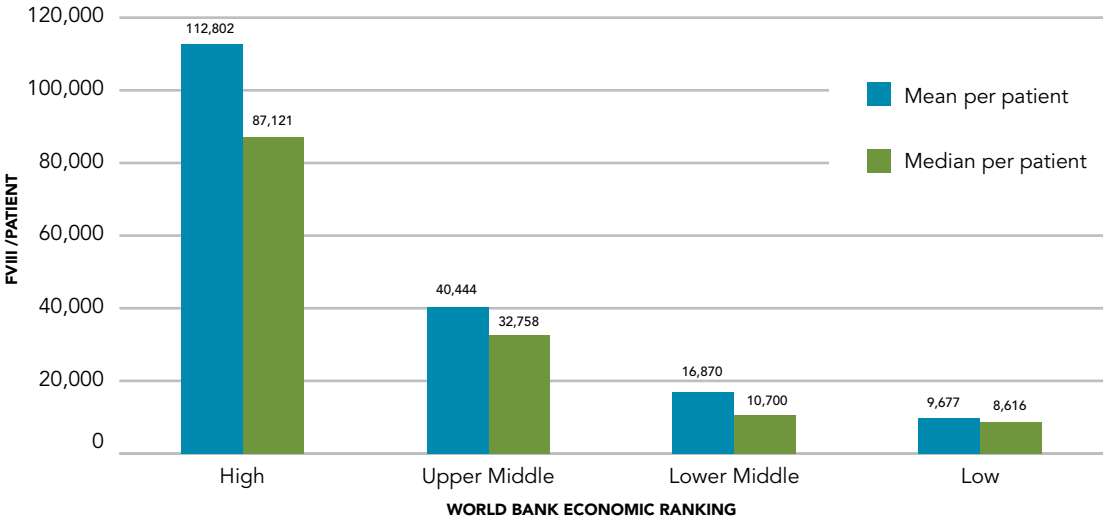

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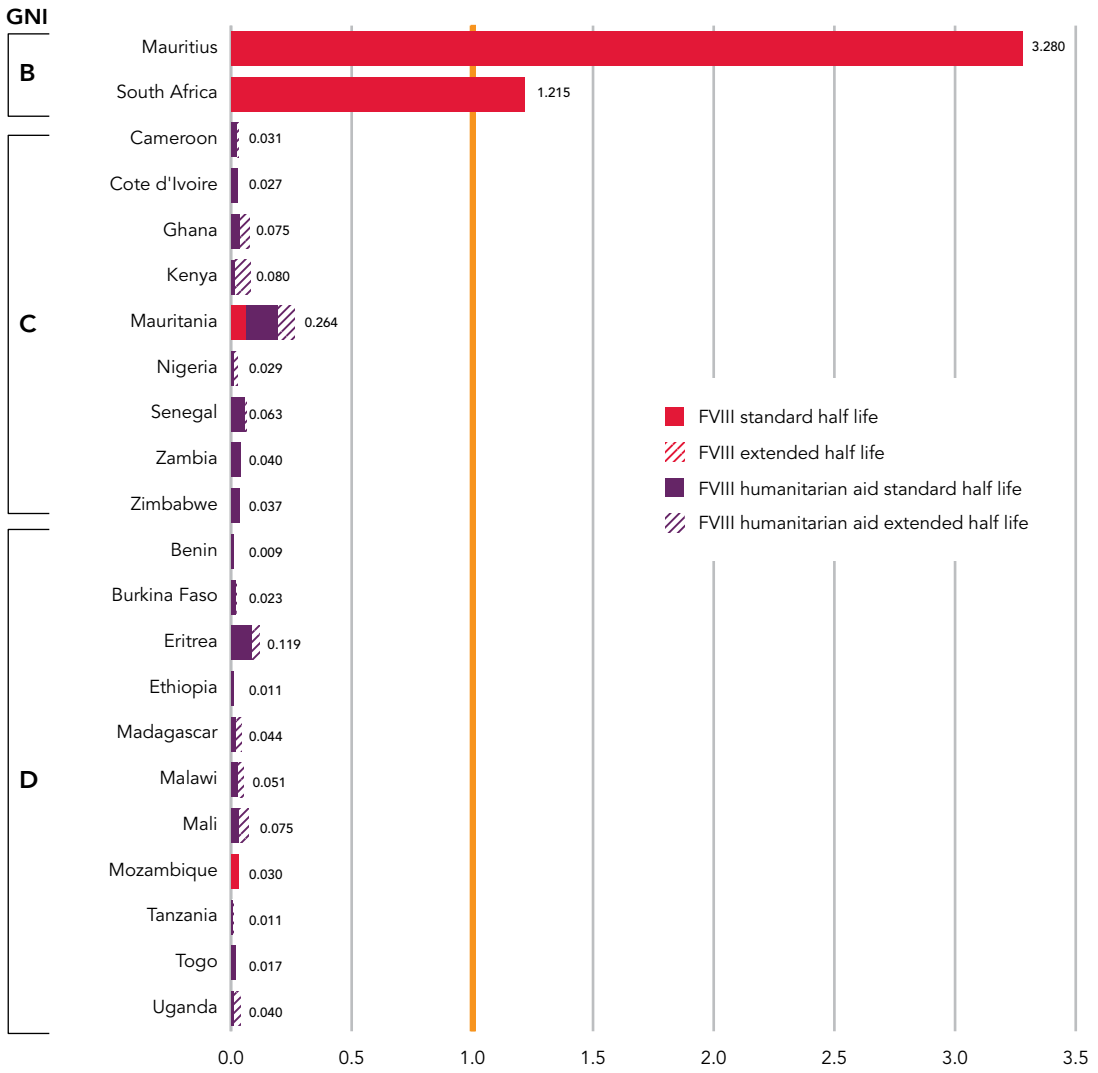
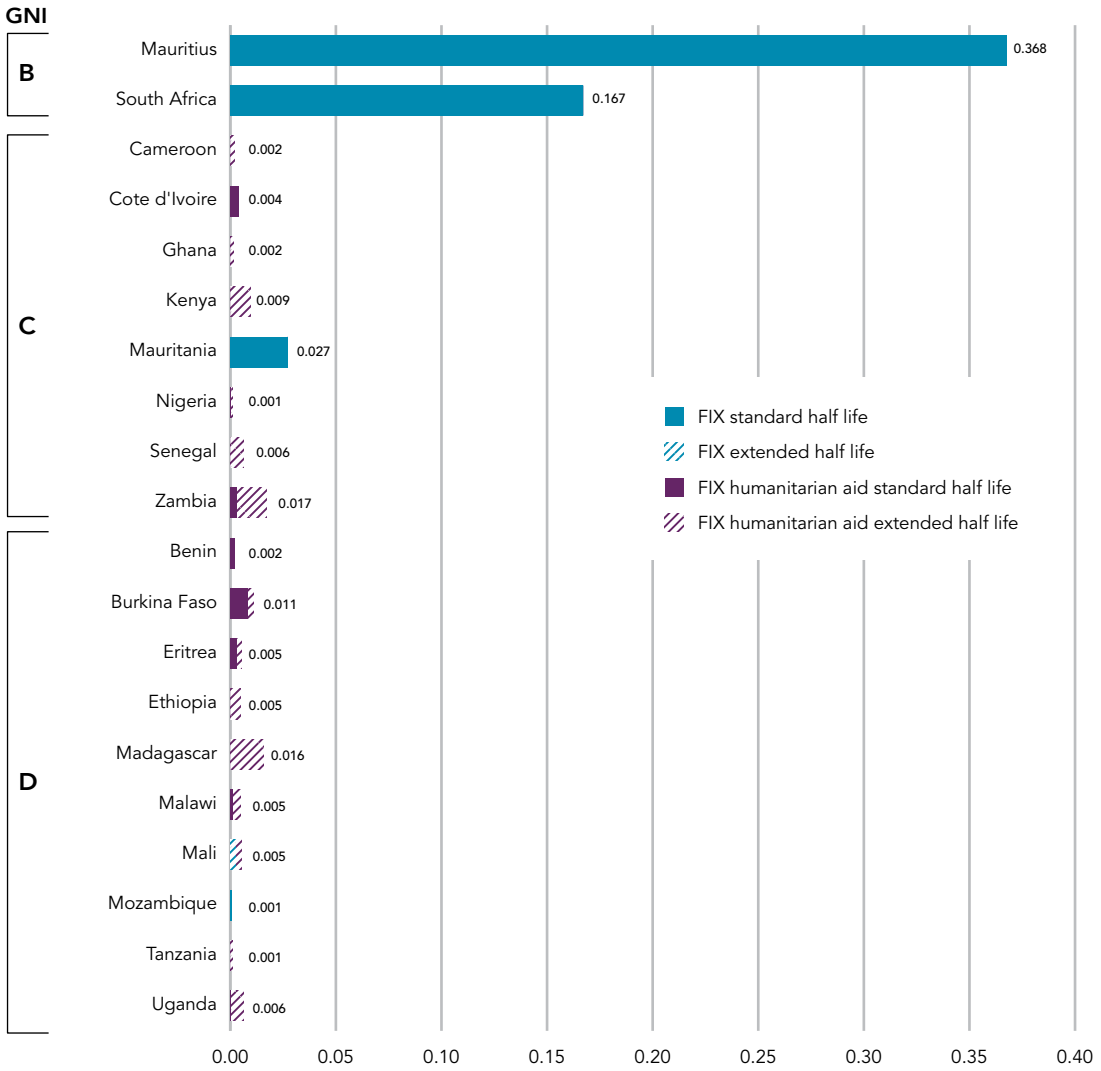
FIGURE F1a. **Mean per capita factor VIII use in 2018 – regional and GNI comparisons of IU/total population: Africa**



Economic category based on The World Bank Group 2018 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure F. The orange line indicates 1 international unit (IU) per capita of factor VIII. The WFH has established that one 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. Only countries that provided product use data in the 2018 questionnaire are included in Figure F graphs. It may be that countries used extended half-life products but did not report the amount. These will be shown as part of the standard half-life products.

FIGURE F1b. **Mean per capita factor IX use in 2018 – regional and GNI comparisons of IU/total population: Africa**



Economic category based on The World Bank Group 2018 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

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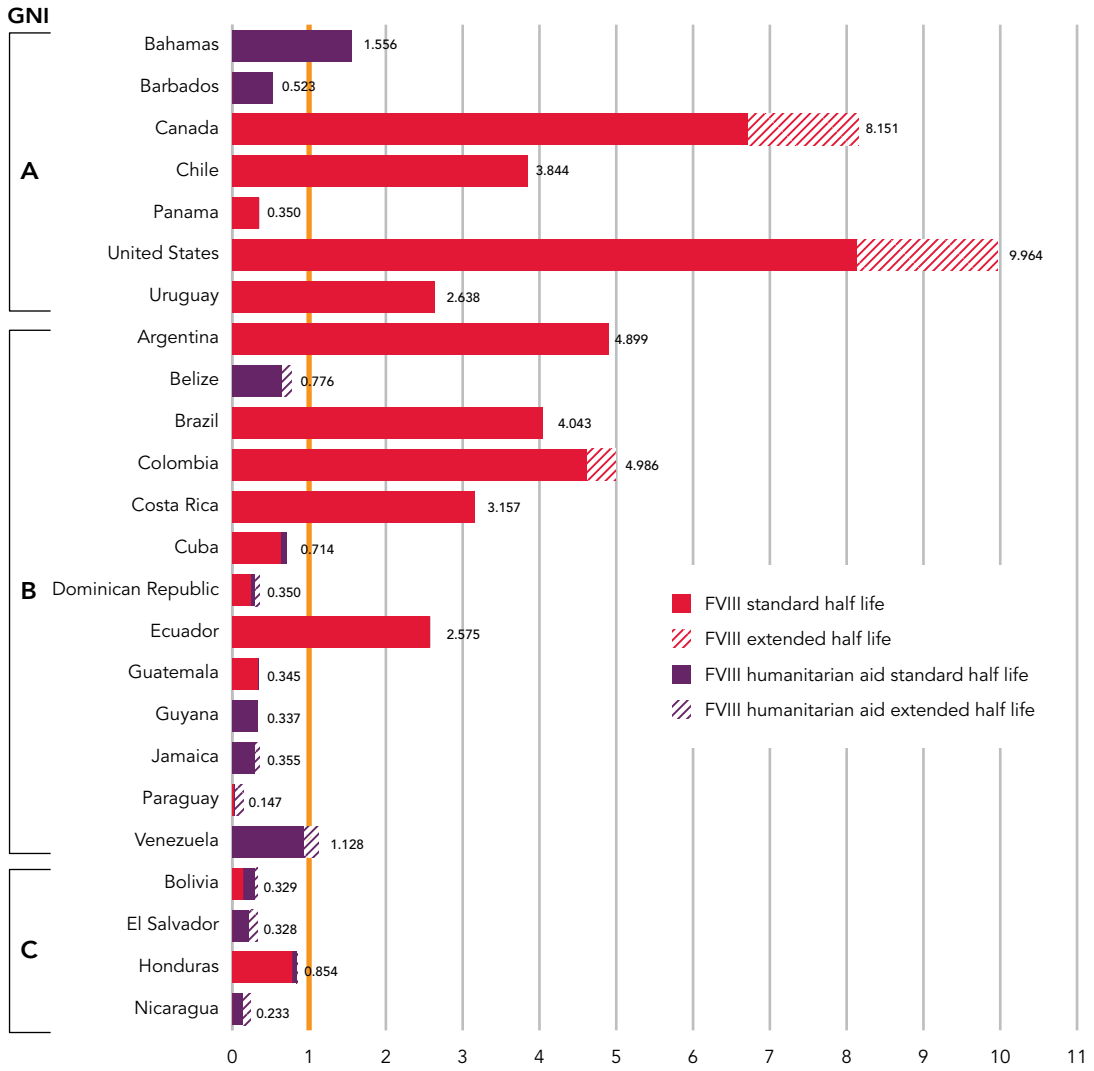
FIGURE F2a. **Mean per capita factor VIII use in 2018 – regional and GNI comparisons of IU/total population: Americas**



Economic category based on The World Bank Group 2018 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

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FIGURE F2b. **Mean per capita factor IX use in 2018 – regional and GNI comparisons of IU/total population: Americas**

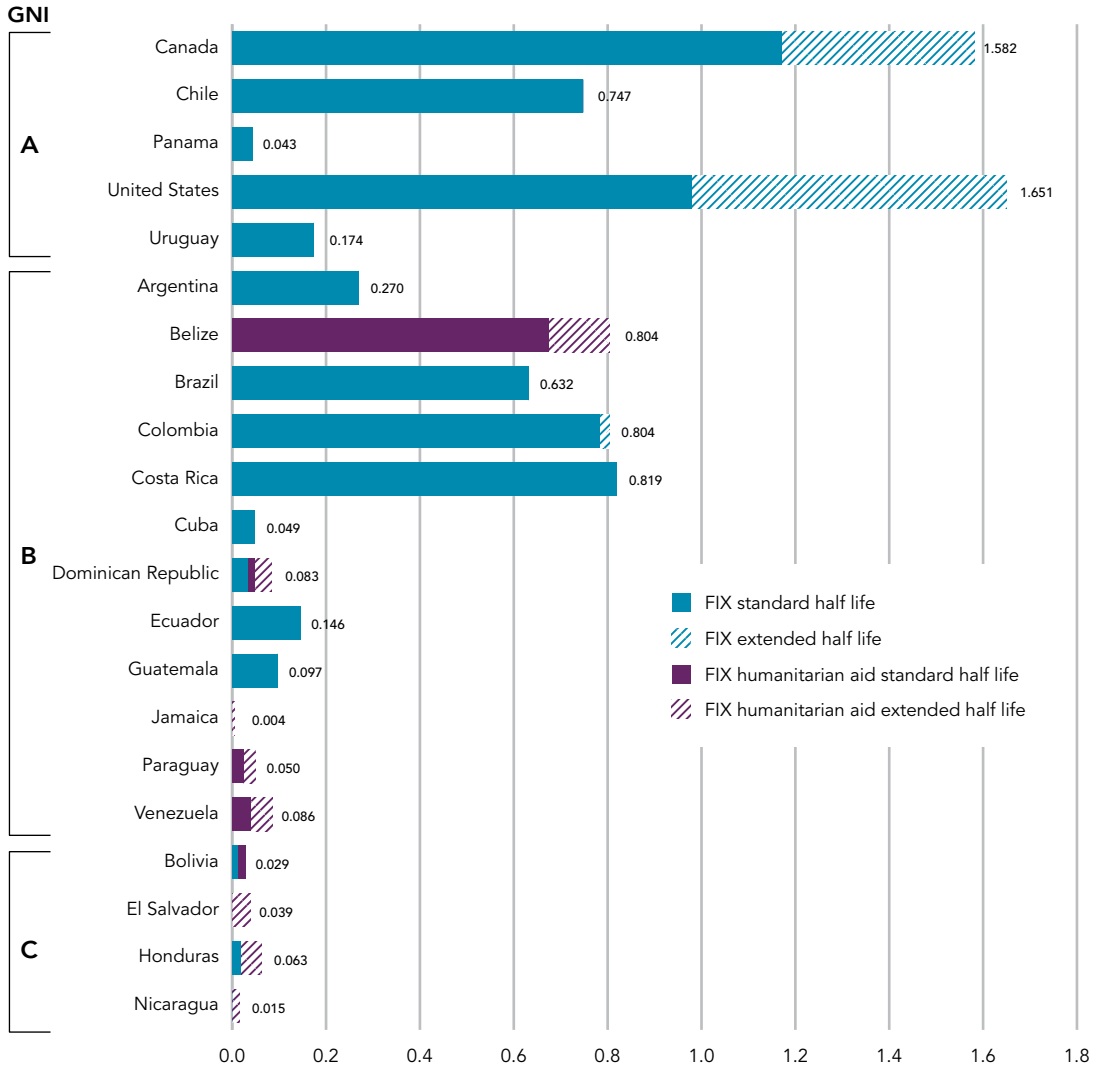

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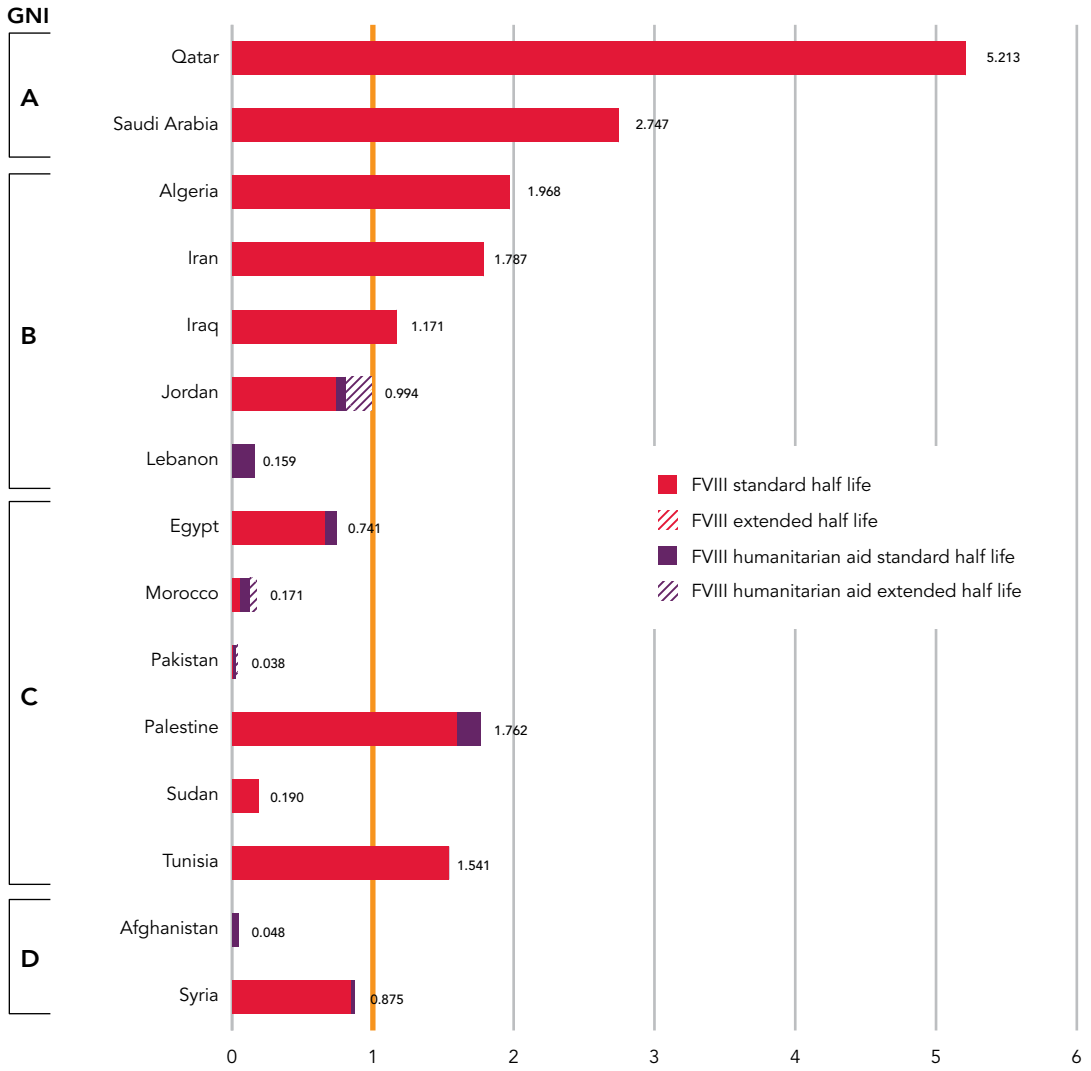
FIGURE F3a. **Mean per capita factor VIII use in 2018 – regional and GNI comparisons of IU/total population: Eastern Mediterranean**



Economic category based on The World Bank Group 2018 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

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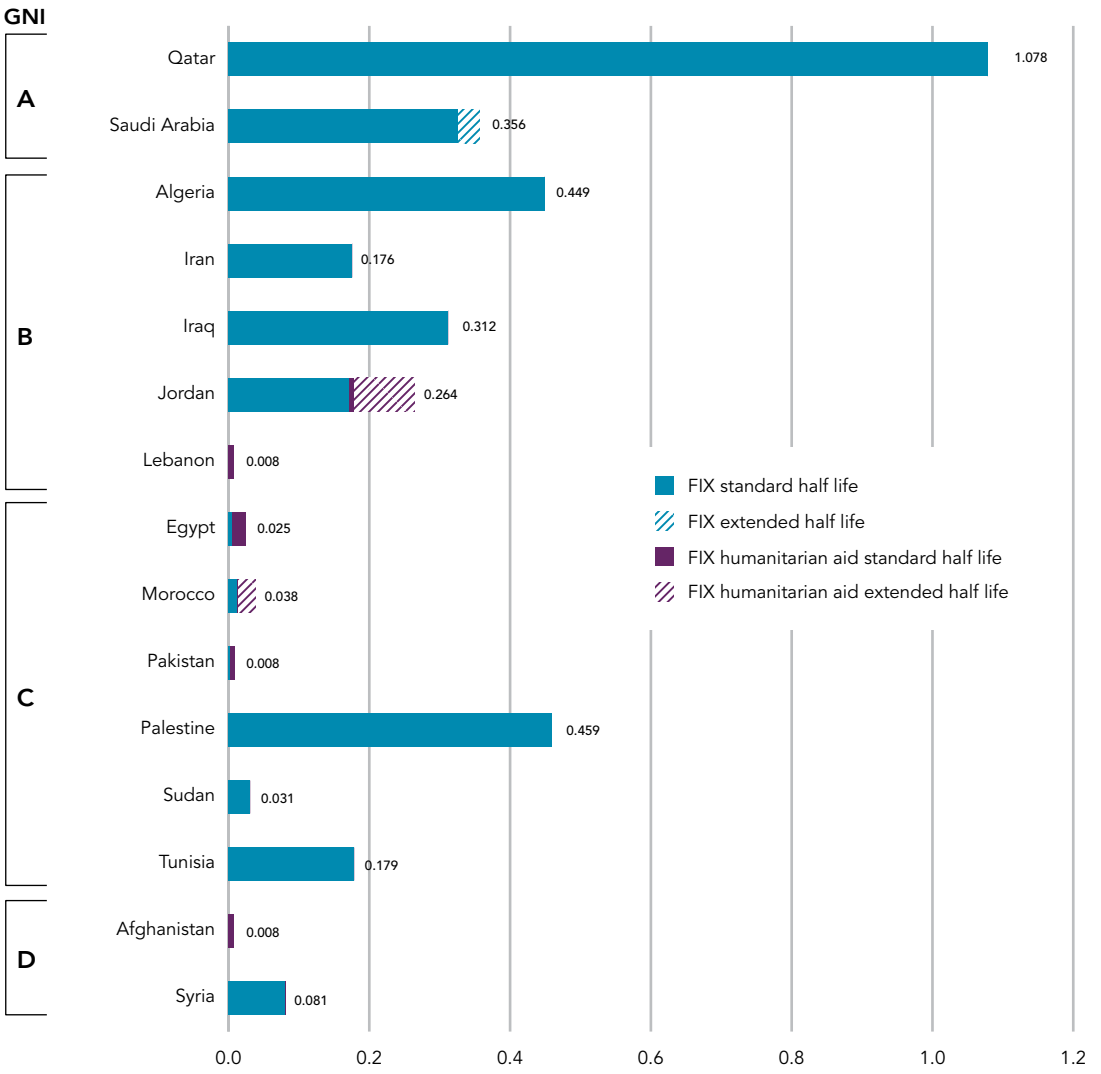
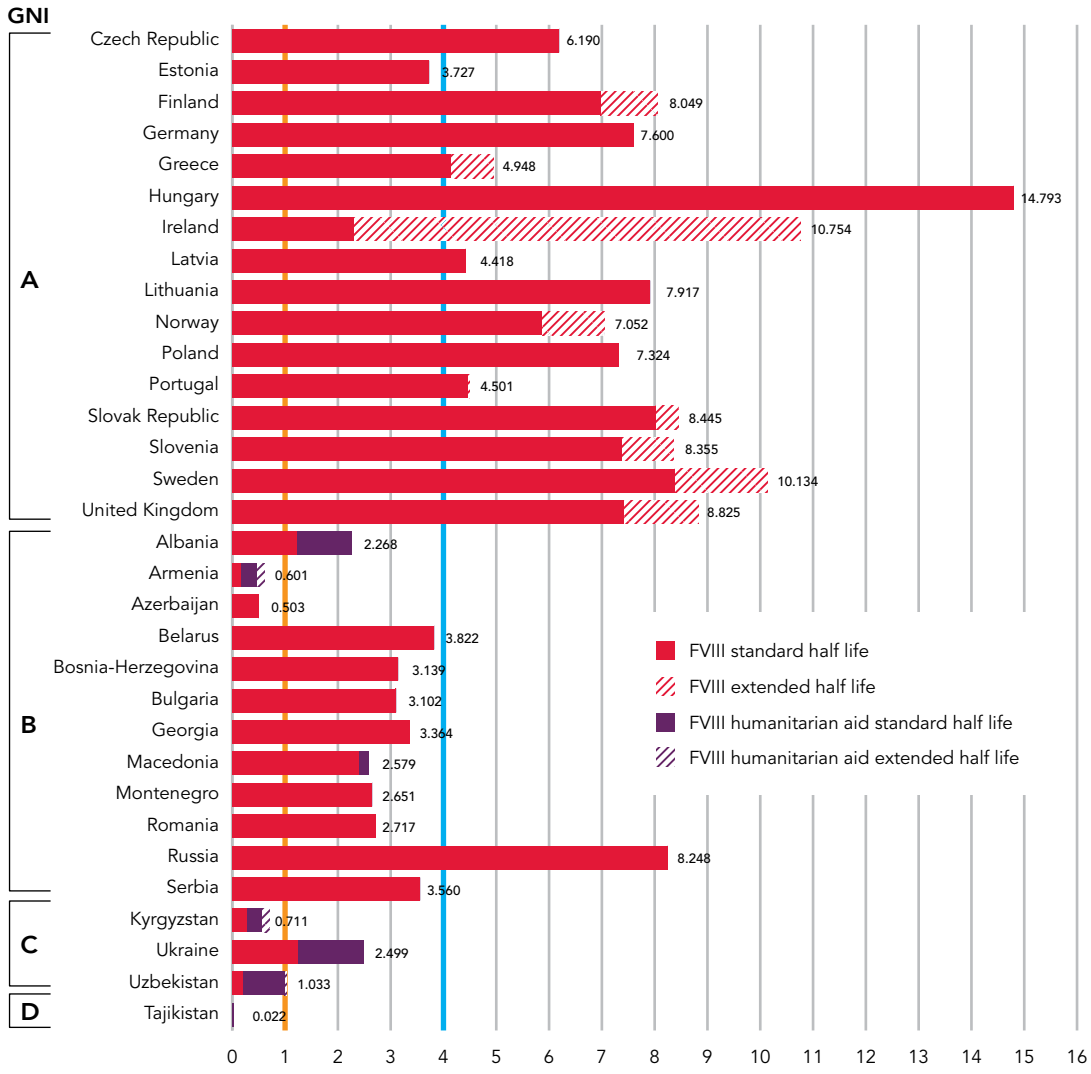
FIGURE F3b. **Mean per capita factor IX use in 2018 – regional and GNI comparisons of IU/total population: Eastern Mediterranean**



Economic category based on The World Bank Group 2018 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure F. Only countries that provided product use data in the 2018 questionnaire are included in Figure F graphs. It may be that countries used extended half-life products but did not report the amount. These will be shown as part of the standard half-life products.

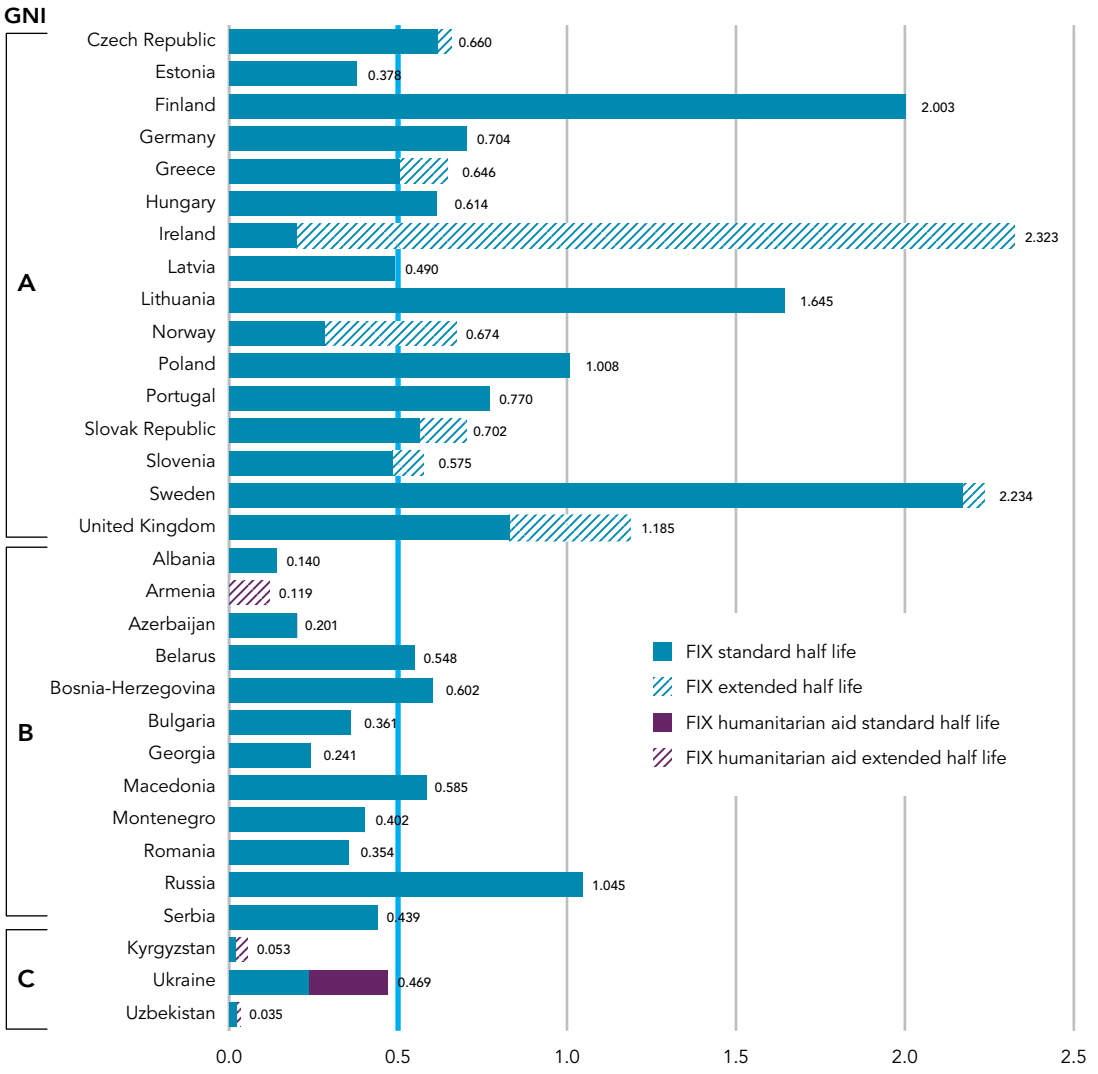
FIGURE F4a. **Mean per capita factor VIII use in 2018 – regional and GNI comparisons of IU/total population: Europe**



Economic category based on The World Bank Group 2018 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure F. The orange line indicates 1 international unit (IU) per capita of factor VIII. The WFH has established that one 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. The European Department for the Quality of Medicines and Healthcare (EDQM) recommends the minimum consumption of factor VIII and IX concentrate in any country should be 4 IU and 0.5 IU per capita of general population respectively. Please note the orange line does not apply to factor IX. Only countries that provided product use data in the 2018 questionnaire are included in Figure F graphs. It may be that countries used extended half-life products but did not report the amount. These will be shown as part of the standard half-life products.

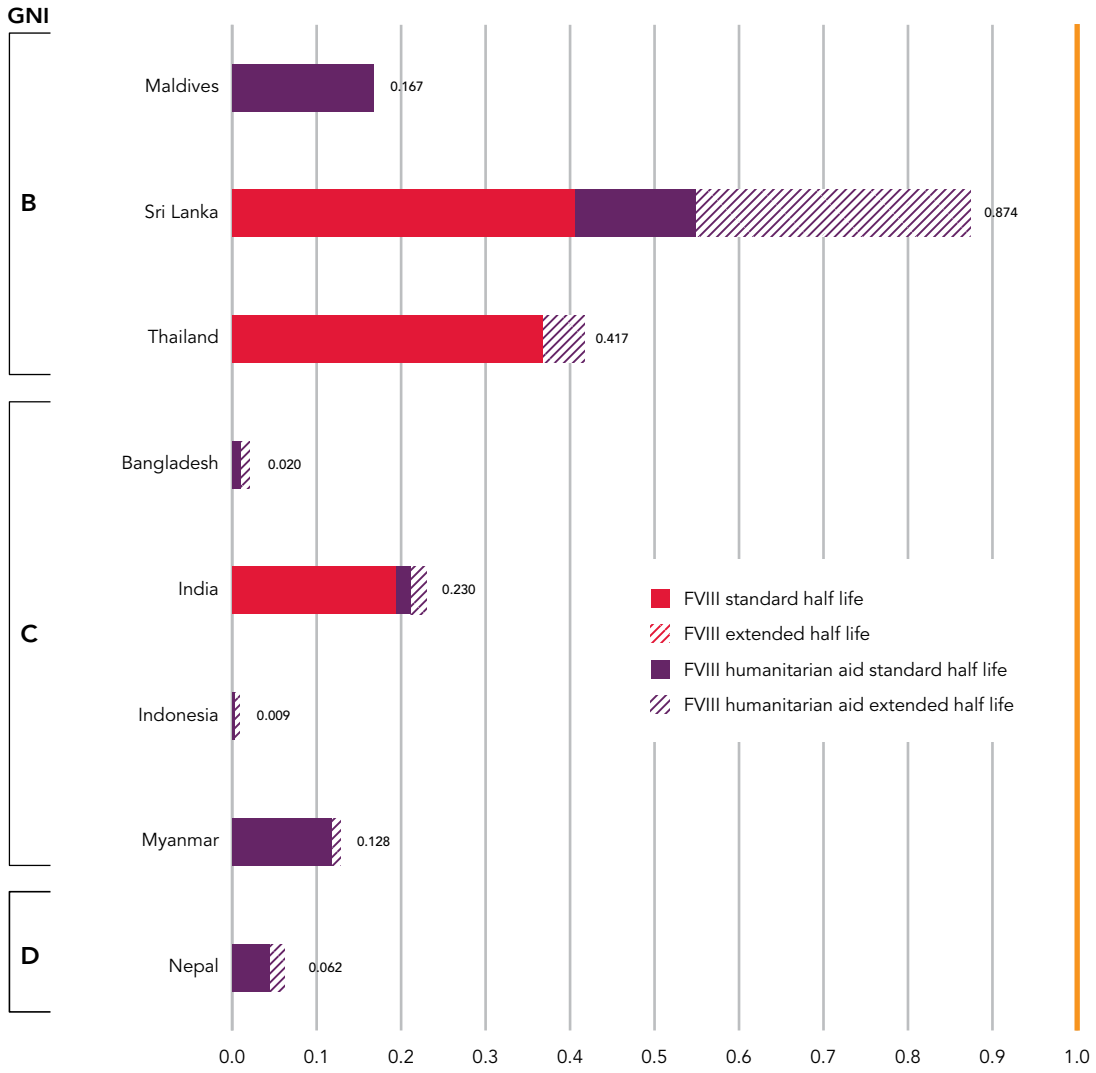
FIGURE F4b. **Mean per capita factor IX use in 2018 – regional and GNI comparisons of IU/total population: Europe**



Economic category based on The World Bank Group 2018 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure F. Only countries that provided product use data in the 2018 questionnaire are included in Figure F graphs. It may be that countries used extended half-life products but did not report the amount. These will be shown as part of the standard half-life products. The European Department for the Quality of Medicines and Healthcare (EDQM) recommends the minimum consumption of factor VIII and IX concentrate in any country should be 4 IU and 0.5 IU per capita of general population respectively.

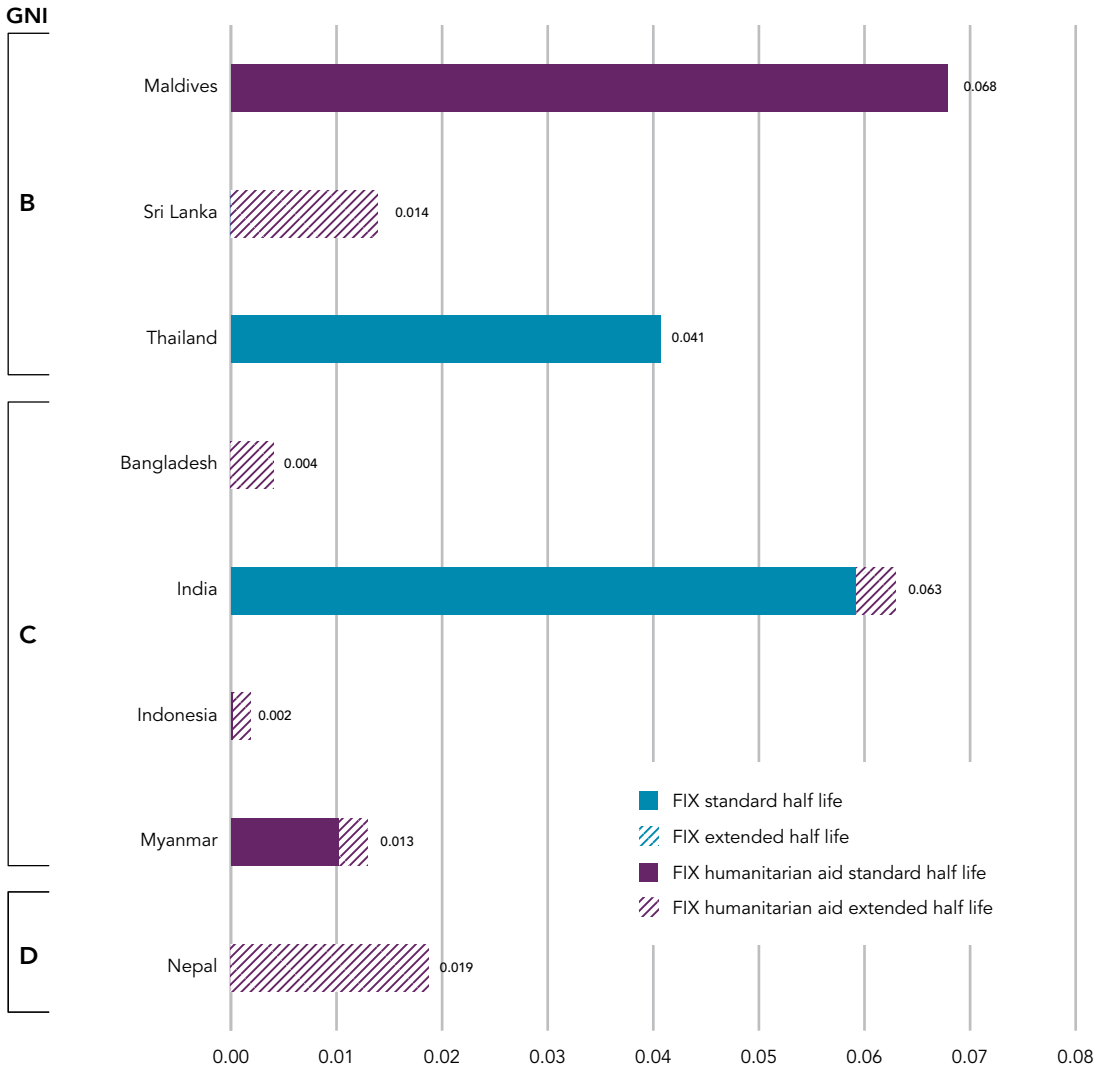
FIGURE F5a. **Mean per capita factor VIII use in 2018 – regional and GNI comparisons of IU/total population: South-East Asia**



Economic category based on The World Bank Group 2018 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure F. The orange line indicates 1 international unit (IU) per capita of factor VIII. The WFH has established that one 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. Only countries that provided product use data in the 2018 questionnaire are included in Figure F graphs. It may be that countries used extended half-life products but did not report the amount. These will be shown as part of the standard half-life products.

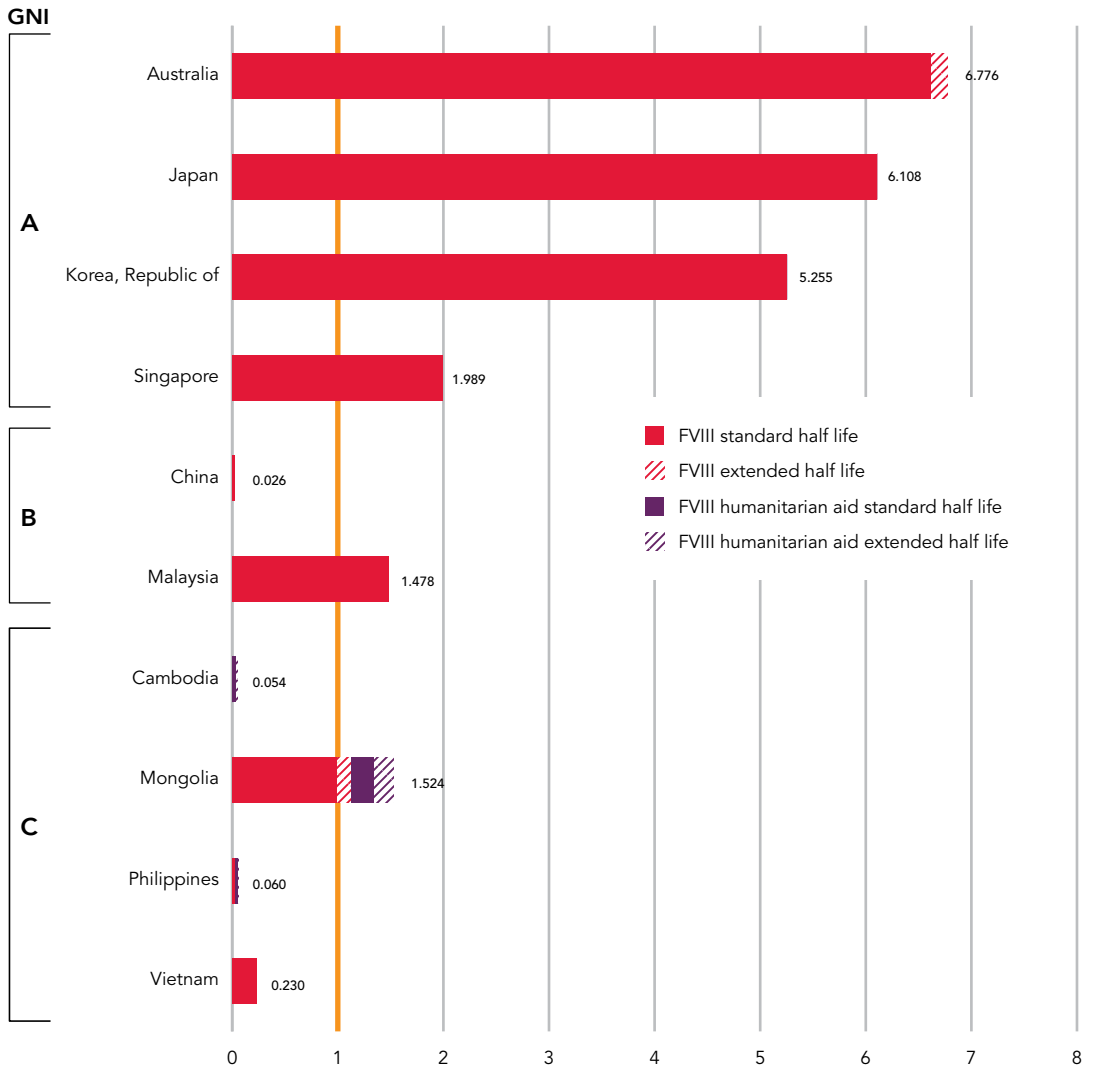
FIGURE F5b. **Mean per capita factor IX use in 2018 – regional and GNI comparisons of IU/total population: South-East Asia**



Economic category based on The World Bank Group 2018 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure F. Only countries that provided product use data in the 2018 questionnaire are included in Figure F graphs. It may be that countries used extended half-life products but did not report the amount. These will be shown as part of the standard half-life products.

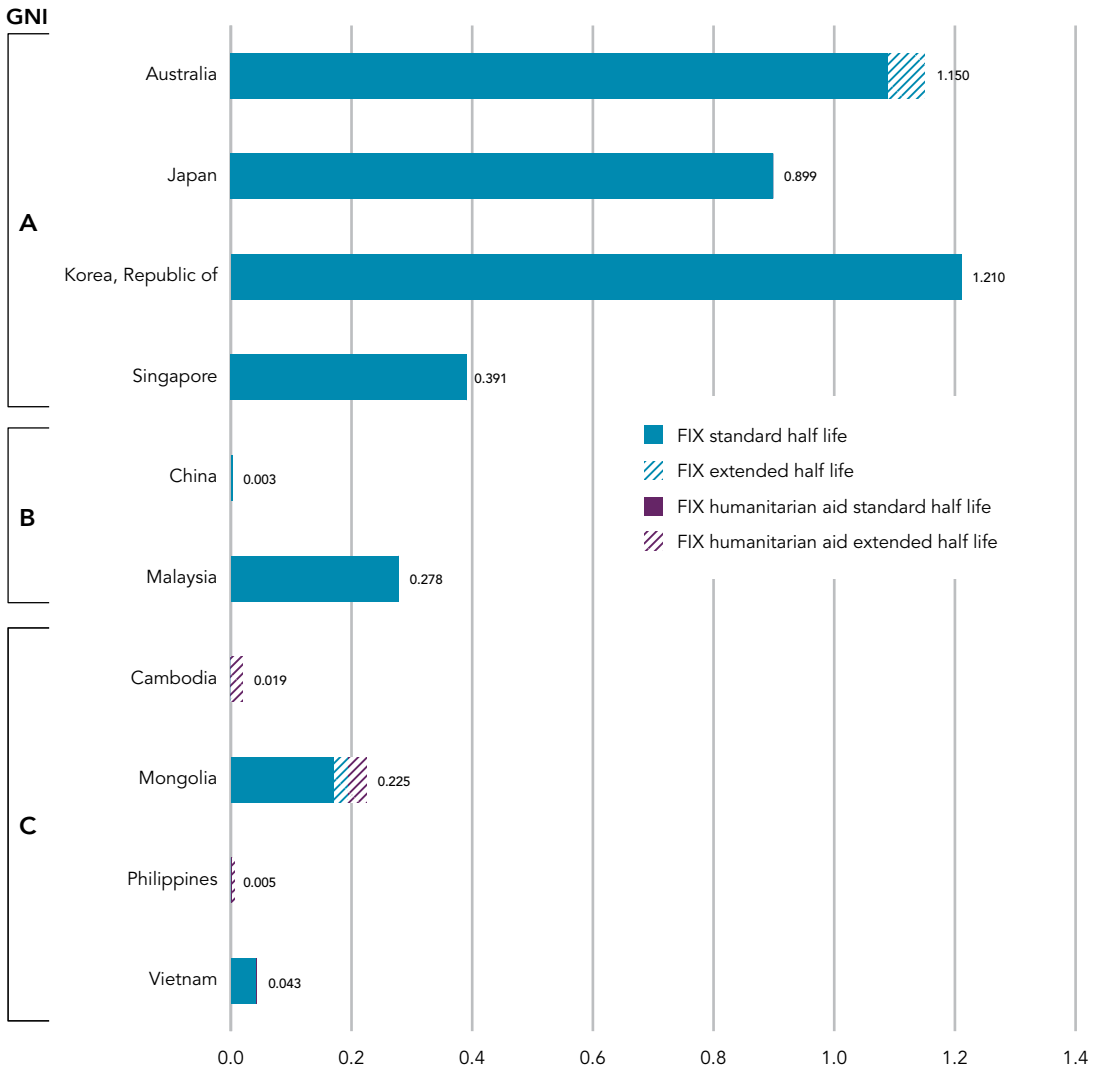
FIGURE F6a. **Mean per capita factor VIII use in 2018 – regional and GNI comparisons of IU/total population: Western Pacific**



Economic category based on The World Bank Group 2018 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure F. The orange line indicates 1 international unit (IU) per capita of factor VIII. The WFH has established that one 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. Only countries that provided product use data in the 2018 questionnaire are included in Figure F graphs. It may be that countries used extended half-life products but did not report the amount. These will be shown as part of the standard half-life products.

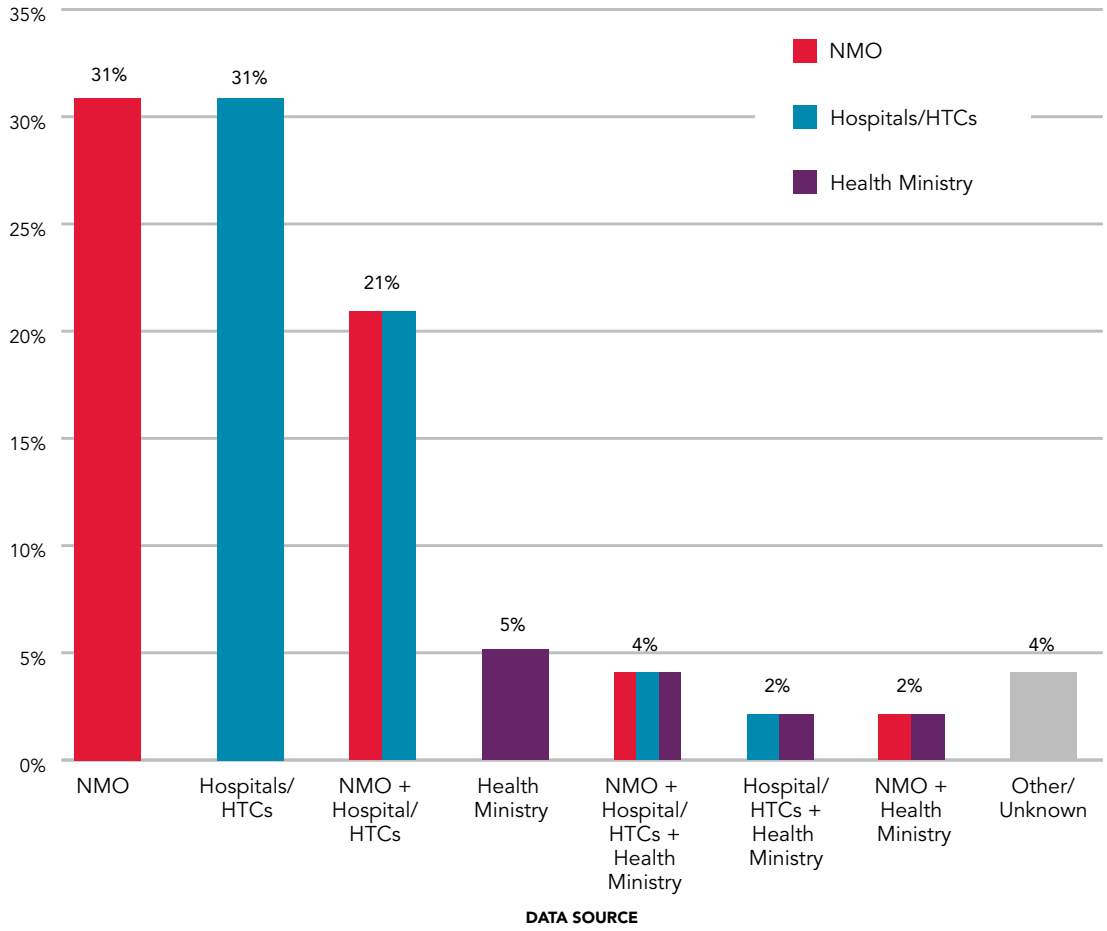
FIGURE F6b. **Mean per capita factor IX use in 2018 – regional and GNI comparisons of IU/total population: Western Pacific**



Economic category based on The World Bank Group 2018 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure F. Only countries that provided product use data in the 2018 questionnaire are included in Figure F graphs. It may be that countries used extended half-life products but did not report the amount. These will be shown as part of the standard half-life products.

FIGURE G. **Data source**

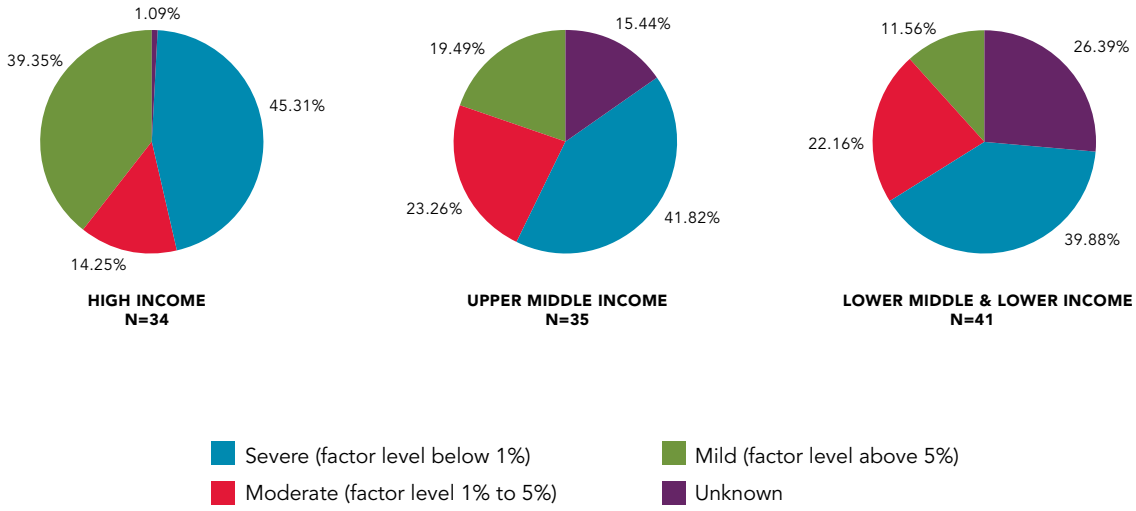


Members were asked the source of the numbers provided for the survey. Possible answers were: Hemophilia Society and/or NMO registry or database, Hospital(s)/HTC(s) registry or database, Health Ministry registry or database or Other. It is possible for members to have used multiple sources to obtain data.

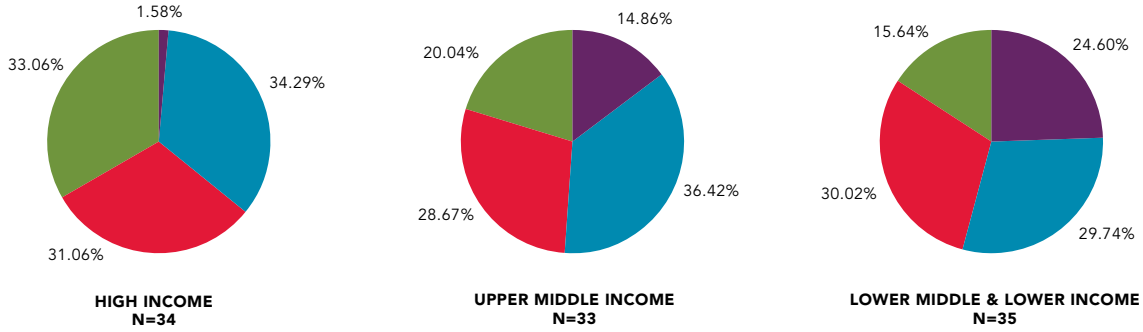
FIGURE H1. **Severity of hemophilia in males by GNI**

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

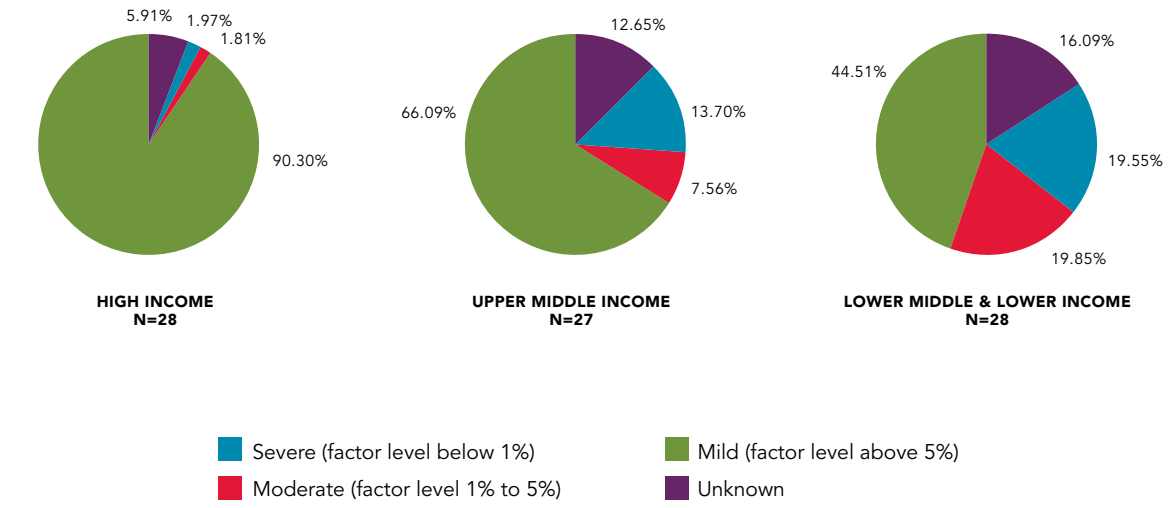


Economic category based on The World Bank Group 2018 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

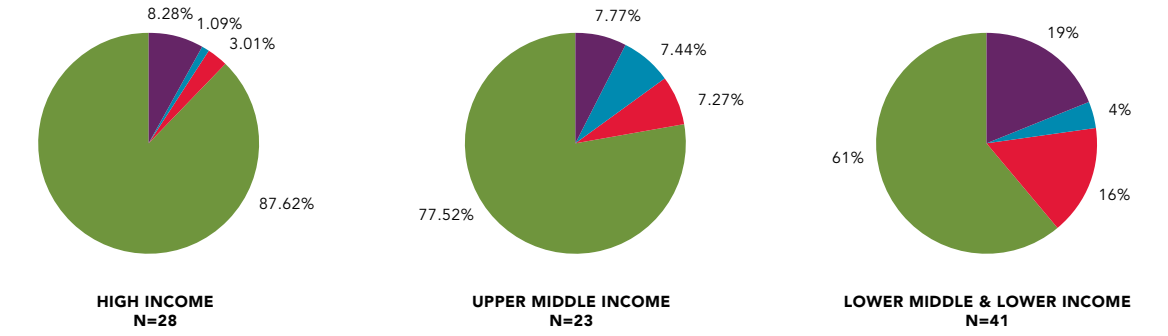
FIGURE H2. **Severity of hemophilia in females–by GNI**

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 2018 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,025; C lower middle income, $1,026–$3,995; B upper middle income, $3,996–$12,375; and A high income, $12,376 or more.

TABLE 6. **National member organizations and their latest year of reporting.**

Please note: the year indicates the latest year the data was submitted. Not all of our members are able to submit data every year. For the 2018 survey report, 125 countries submitted data and can be found in **BOLD** in the table below.

Country	Last year of submission	Total number of submissions
Afghanistan	2018	3
Albania	2018	15
Algeria	2018	15
Argentina	2018	19
Armenia	2018	9
Australia	2018	20
Austria	2018	14
Azerbaijan	2018	14
Bahamas	2018	1
Bahrain	2014	5
Bangladesh	2018	18
Barbados	2018	2
Belarus	2018	12
Belgium	2018	18
Belize	2018	12
Benin	2018	1
Bolivia	2018	7
Bosnia-Herzegovina	2018	5
Botswana	2018	2
Brazil	2018	19
Bulgaria	2018	10
Burkina Faso	2018	3
Cambodia	2018	12
Cameroon	2018	12
Canada	2018	19
Chile	2018	11
China	2018	12
Colombia	2018	19
Costa Rica	2018	19
Cote d'Ivoire	2018	11
Croatia	2007	6
Cuba	2018	16
Cyprus	2013	7
Czech Republic	2018	13
Denmark	2018	14
Dominican Republic	2018	17
Ecuador	2018	14
Egypt	2018	17
El Salvador	2018	7
Eritrea	2018	11
Estonia	2018	10
Ethiopia	2018	8
Finland	2018	14
France	2018	16
Georgia	2018	17
Germany	2018	20
Ghana	2018	8
Greece	2018	19
Guatemala	2018	9
Guyana	2018	2
Honduras	2018	17
Hong Kong (China)	2018	3
Hungary	2018	17
Iceland	2007	6
India	2018	18
Indonesia	2018	15
Iran	2018	19
Iraq	2018	15
Ireland	2018	20
Israel	2018	13
Italy	2018	12
Jamaica	2018	7
Japan	2018	19
Jordan	2018	9

Country	Last year of submission	Total number of submissions
Kazakhstan	2008	1
Kenya	2018	17
Korea, Republic of	2018	20
Kyrgyzstan	2018	7
Latvia	2018	19
Lebanon	2018	9
Lesotho	2018	12
Lithuania	2018	19
Luxembourg	2001	3
Macedonia	2018	9
Madagascar	2018	3
Malawi	2018	3
Malaysia	2018	18
Maldives	2018	5
Mali	2018	3
Mauritania	2018	2
Mauritius	2018	8
Mexico	2018	17
Moldova	2017	11
Mongolia	2018	12
Montenegro	2018	4
Morocco	2018	6
Mozambique	2018	2
Myanmar	2018	2
Namibia	2018	1
Nepal	2018	19
Netherlands	2018	14
New Zealand	2018	20
Nicaragua	2018	14
Nigeria	2018	11
Norway	2018	14
Oman	2016	6
Pakistan	2018	18
Palestine	2018	8
Panama	2018	17
Paraguay	2018	6
Peru	2015	10
Philippines	2018	16

Country	Last year of submission	Total number of submissions
Poland	2018	20
Portugal	2018	20
Qatar	2018	8
Romania	2018	15
Russia	2018	19
Saudi Arabia	2018	11
Senegal	2018	14
Serbia	2018	12
Sierra Leone	1999	1
Singapore	2018	10
Slovak Republic	2018	17
Slovenia	2018	13
South Africa	2018	19
Spain	2013	13
Sri Lanka	2018	10
Sudan	2018	15
Suriname	2018	2
Sweden	2018	14
Switzerland	2017	16
Syria	2018	8
Tajikistan	2018	1
Tanzania	2018	7
Thailand	2018	18
Togo	2018	7
Trinidad and Tobago	N/A	0
Tunisia	2018	13
Turkey	2014	16
Uganda	2018	8
Ukraine	2018	11
United Arab Emirates	2015	1
United Kingdom	2018	19
United States	2018	19
Uruguay	2018	11
Uzbekistan	2018	16
Venezuela	2018	20
Vietnam	2018	16
Zambia	2018	4
Zimbabwe	2018	14

TABLE 7. **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.

The population data is sourced from The World Bank Group.

Country	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Afghanistan	37,172,386	441	0	0
Albania	2,866,376	224	6	8
Algeria	42,228,429	2,342	360	669
Argentina	44,494,502	2,711	397	10
Armenia	2,951,776	312	28	63
Australia	24,992,369	2,653	2,146	840
Austria	8,847,037	775	Not Known	Not Known
Azerbaijan	9,942,334	1,569	214	106
Bahamas	385,640	9	2	0
Bangladesh	161,356,039	1,675	2	1
Barbados	286,641	35	1	0
Belarus	9,485,386	591	195	47
Belgium	11,422,068	1,258	2,056	503
Belize	383,071	18	Not Known	Not Known
Benin	11,485,048	83	0	73
Bolivia	11,353,142	139	2	Not Known
Bosnia-Herzegovina	3,323,929	180	Not Known	Not Known
Botswana	2,254,126	43	5	0
Brazil	209,469,333	12,653	8,957	3,492
Bulgaria	7,024,216	620	90	32
Burkina Faso	19,751,535	75	Not Known	Not Known
Cambodia	16,249,798	189	6	6
Cameroon	25,216,237	156	3	Not Known
Canada	37,058,856	3,687	4,321	2,057
Chile	18,729,160	1,744	452	751
China	1,392,730,000	18,712	149	186
Colombia	49,648,685	3,230	2,770	524
Costa Rica	4,999,441	219	87	86
Cote d'Ivoire	25,069,229	96	3	3

Country	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Cuba	11,338,138	494	386	3,406
Czech Republic	10,625,695	1,003	760	148
Denmark	5,797,446	490	249	Not Known
Dominican Republic	10,627,165	368	39	52
Ecuador	17,084,357	854	99	6
Egypt	98,423,595	6,028	583	1,323
El Salvador	6,420,744	234	2	0
Eritrea	5,869,869	60	Not Known	Not Known
Estonia	1,320,884	112	113	102
Ethiopia	109,224,559	328	Not Known	2
Finland	5,518,050	256	547	Not Known
France	66,987,244	7,944	2,479	1,033
Georgia	3,731,000	323	39	33
Germany	82,927,922	4,139	3,777	Not Known
Ghana	29,767,108	300	8	Not Known
Greece	10,727,668	999	1,100	465
Guatemala	17,247,807	324	23	11
Guyana	779,004	15	Not Known	11
Honduras	9,587,522	360	18	2
Hong Kong (China)	7,451,000	175	1	5
Hungary	9,768,785	1,144	1,471	506
India	1,352,617,328	20,778	676	457
Indonesia	267,663,435	2,345	17	Not Known
Iran	81,800,269	6,317	1,644	3,449
Iraq	38,433,600	2,369	480	546
Ireland	4,853,506	958	1,693	1,164
Israel	8,883,800	712	168	719
Italy	60,431,283	5,021	2,854	2,568
Jamaica	2,934,855	47	2	7
Japan	126,529,100	6,457	1,325	387
Jordan	9,956,011	394	252	112
Kenya	51,393,010	618	30	20
Korea, Republic of	51,635,256	2,323	135	175
Kyrgyzstan	6,315,800	383	16	7
Latvia	1,926,542	114	101	11
Lebanon	6,848,925	216	159	70

Country	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Lesotho	2,108,132	28	Not Known	2
Lithuania	2,789,533	177	305	17
Macedonia	2,082,958	320	167	12
Madagascar	26,262,368	127	2	12
Malawi	18,143,315	41	0	Not Known
Malaysia	31,528,585	1,075	132	72
Maldives	515,696	19	Not Known	Not Known
Mali	19,077,690	141	20	14
Mauritania	4,403,319	76	Not Known	Not Known
Mauritius	1,265,303	87	1	9
Mexico	126,190,788	5,814	328	59
Mongolia	3,170,208	109	13	Not Known
Montenegro	622,345	45	3	5
Morocco	36,029,138	217	22	72
Mozambique	29,495,962	76	1	4
Myanmar	53,708,395	547	19	4
Namibia	2,448,255	69	0	4
Nepal	28,087,871	682	5	22
Netherlands	17,231,017	922	140	38
New Zealand	4,885,500	556	405	101
Nicaragua	6,465,513	315	89	7
Nigeria	195,874,740	397	7	0
Norway	5,314,336	422	602	88
Pakistan	212,215,030	1,982	294	128
Palestine	4,569,087	719	7	10
Panama	4,176,873	71	128	67
Paraguay	6,956,071	397	1	1
Philippines	106,651,922	1,527	43	Not Known
Poland	37,978,548	2,870	1,980	813
Portugal	10,281,762	705	51	23
Qatar	2,781,677	53	37	13
Romania	19,473,936	1,825	87	Not Known
Russia	144,478,050	7,451	1,950	Not Known
Saudi Arabia	33,699,947	637	241	336
Senegal	15,854,360	238	10	11
Serbia	6,982,084	545	301	54

Country	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Singapore	5,638,676	259	88	79
Slovak Republic	5,447,011	607	696	1,116
Slovenia	2,067,372	247	186	85
South Africa	57,779,622	2,332	647	220
Sri Lanka	21,670,000	1,005	56	52
Sudan	41,801,533	1,187	308	389
Suriname	575,991	16	3	0
Sweden	10,183,175	936	203	Not Known
Syria	16,906,283	859	108	164
Tajikistan	9,100,837	457	15	29
Tanzania	56,318,348	148	Not Known	Not Known
Thailand	69,428,524	1,660	200	216
Togo	7,889,094	46	2	Not Known
Tunisia	11,565,204	560	186	291
Uganda	42,723,139	221	2	Not Known
Ukraine	44,622,516	2,188	469	5
United Kingdom	66,488,991	8,348	10,969	9,504
United States	327,167,434	17,757	11,805	6,700
Uruguay	3,449,299	276	258	21
Uzbekistan	32,955,400	1,673	126	43
Venezuela	28,870,195	2,829	1,166	1,101
Vietnam	95,540,395	3,820	159	372
Zambia	17,351,822	130	5	Not Known
Zimbabwe	14,439,018	170	1	1

TABLE 8. **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.

Country	Hemophilia A	Hemophilia B	Hemophilia type unknown	vWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXIII	Bleeding disorder: type unkown	Glanzmann's thrombasthenia	Bernard-Soulier syndrome	Platelet disorders: other/ unknown
Afghanistan	402	39														
Albania	190	33	1	6	0	0	0	0	4	2	0	2				
Algeria	1,914	428		360	52	8	60	29	400	22	14	19	20	30	15	
Argentina	2,341	370	0	397	0	0	0	1	2	0	1	1	0	2	0	3
Armenia	230	19	63	28	2	1	1	3	19	2	8	1	2	6	3	15
Australia	2,152	501		2,146	91		15		83	19	287	42		25	8	270
Austria	658	117	0													
Azerbaijan	1,357	212		214	1	7	18	24	18	7	8	9		5	9	
Bahamas	7	1	1	2	0	0	0	0	0	0	0	0	0	0	0	0
Bangladesh	1,402	267	6	2								1				
Barbados	22	13		1												
Belarus	485	106	0	195	0	0	0	0	19	3	25	0	0			
Belgium	1,007	242	9	2,056	2	2	21	0	136	9	135	4	30	20	4	140
Belize	13	5														
Benin	73	3	7													
Bolivia	117	22		2												
Bosnia-Herzegovina	154	26														
Botswana	36	7	0	5												
Brazil	10,558	2,095	0	8,957	134	22	239	42	1,397	138	259	75	0	647	101	438
Bulgaria	551	68	1	90		1			5	3	2	2	8	11		
Burkina Faso	53	22	0													
Cambodia	161	27	1	6								1				5
Cameroon	133	23	0	3												
Canada	3,018	669	0	4,321	158	16	75	0	486	47	476	54	0	25	66	654
Chile	1,506	173	65	452	0	0	22	7	284	15	44	0	2	5	4	368
China	16,158	2,460	94	149			15	8	49	6	61	6	21	20		
Colombia	2,639	591		2,770	64	11	50	14	132	37	84	53	36	15	2	26
Costa Rica	183	36	0	87	4	0	2	13	46	11	7	3				
Cote d'Ivoire	83	13	0	3	0	0	0	0	1	2	0	0	0	0	0	0
Cuba	415	79	0	386	2	1	2	0	2	2	15	7	21	2	0	3,352
Czech Republic	867	136	0	760	0	4	9	0	81	6	29	2	17			
Denmark	388	102		249												

Country	Hemophilia A	Hemophilia B	Hemophilia type unknown	vWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXIII	Bleeding disorder: type unkown	Glanzmann's thrombasthenia	Bernard-Soulier syndrome	Platelet disorders: other/ unknown
Dominican Republic	302	37	29	39					6	39		5		2		
Ecuador	755	99		99					5			1				
Egypt	4,885	1,143	0	583	159	8	180	8	194	117	101	44	5	487	20	0
El Salvador	105	12	117	2	0	0	0	0	0	0	0	0	0	0	0	0
Eritrea	54	6														
Estonia	102	10		113	11	1	6	1	31		7		31		2	12
Ethiopia	145	28	155											2		
Finland	169	33	54	547												
France	6,446	1,498		2,479	42	1	55	18	197	27	211	33	0	209	51	189
Georgia	270	53		39	1		1		18			2		6		5
Germany	3,511	628		3,777												
Ghana	278	16	6	8												
Greece	815	184	0	1,100	28	2	37	1	145	12	105	12	0	13	13	97
Guatemala	250	34	40	23	0	0	0	0	9	0	1	0	0	1	0	0
Guyana	13		2					11								
Honduras	299	34	27	18								2				
Hong Kong (China)	119	24	32	1	0	0	0	0	3	2	0	0	0			
Hungary	914	230	0	1,471	16	1	22	0	333	22	80	3		3		26
India	17,606	2,715	457	676	27	10	56	12	72	43	33	117		66	21	
Indonesia	2,035	310		17												
Iran	5,208	1,109	0	1,644	157	26	244	243	786	207	260	260	218	601	102	345
Iraq	1,867	502		480	60	2	15	4	145	30	12	60		118	23	77
Ireland	715	243	0	1,693	1	3	171	2	203	152	263	11	0	13	4	341
Israel	608	104		168	5	0	9	14	90	9	372	8		42	5	165
Italy	4,135	886	0	2,854	208	24	167	36	1,109	117	511	129				267
Jamaica	43	4	0	2	0	0	0	0	0	6	0	0	0	1	0	0
Japan	5,301	1,156		1,325	84	7	45	9	107	22	39	74				
Jordan	298	96		252										112		
Kenya	504	114	0	30	1				1		1					17
Korea, Republic of	1,721	427	175	135	7		6	3	45	2	23	5	84			
Kyrgyzstan	343	40		16	1	1								5		
Latvia	93	21	0	101	0	0	2	0	7	2	0	0	0	0	0	0
Lebanon	169	47	0	159	35	0	9	1	7	5	5	2	0	1	0	5
Lesotho	24	2	2								2					
Lithuania	152	24	1	305					12	2						3
Macedonia	213	107		167	2				2		2	6				

Country	Hemophilia A	Hemophilia B	Hemophilia type unknown	vWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXIII	Bleeding disorder: type unkown	Glanzmann's thrombasthenia	Bernard-Soulier syndrome	Platelet disorders: other/ unknown
Madagascar	70	57		2	12											
Malawi	35	6		0												
Malaysia	900	172	3	132	0	4	4	0	9	10	9	11	0	20	3	2
Maldives	14	4	1													
Mali	128	13	0	20	1	0	0	0	1	0	0	1	10	0	0	1
Mauritania	61	15														
Mauritius	74	13	0	1	0	0	0	0	3	1	0	0	2	3	0	0
Mexico	4,761	724	329	328	0	1	3	0	27	5	8	3	4	4	0	4
Mongolia	81	28		13												
Montenegro	41	4	0	3	0	0	0	0	1	0	1	3	0	0	0	0
Morocco	183	34		22	8	4	7	4	15	1	3	3	3	21	2	1
Mozambique	60	16		1			1	2	1							
Myanmar	464	76	7	19	0	0	0	0	2	2	0	0	0	0	0	0
Namibia	55	10	4											1	3	
Nepal	562	93	27	5		1	1	1	3	13		3				
Netherlands	797	125	0	140	4	2	0	1	10	2	2	7	1	3	0	6
New Zealand	454	102		405					12	5	5	5	3	2	1	68
Nicaragua	261	54	0	89	4	0	0	0	0	0	0	0	1	2	0	0
Nigeria	367	12	18	7	0	0	0	0	0	0	0	0	0	0	0	0
Norway	332	90	0	602	2	2	4	0	34	3	1	3	0	12	4	23
Pakistan	1,678	304	0	294	8	4	19	1	27	23	1	23	1	19	2	0
Palestine	284	39	396	7			8		2							
Panama	61	10	0	128	0	0	0	0	6	4	0	0	0	8	0	49
Paraguay	369	28		1					1							
Philippines	1,124	193	210	43												
Poland	2,442	428		1,980	116	1	31	3	309	26	72	11		27	9	208
Portugal	541	112	52	51	2	0	3	0	2	1	6	1	2	5	0	1
Qatar	47	6	0	37	0	0	0	0	3	0	0	2	0	5	2	1
Romania	1,615	210		87												
Russia	6,342	1,109		1,950												
Saudi Arabia	511	126	0	241	5	18	31	2	27	24	15	60	0	121	10	23
Senegal	208	30		10	1		1		3	1				2		3
Serbia	460	85	0	301	8	0	2	2	26	1	8	4	1	0	2	0
Singapore	213	46	0	88	0	0	18	0	9	0	47	5	0	0	0	0
Slovak Republic	528	79	0	696	93	0	76	1	804	37	55	2	0	10	15	23
Slovenia	217	30	0	186	4	0	12	3	16	2	21	0	0	7	0	20

Country	Hemophilia A	Hemophilia B	Hemophilia type unknown	vWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXIII	Bleeding disorder: type unkown	Glanzmann's thrombasthenia	Bernard-Soulier syndrome	Platelet disorders: other/ unknown
South Africa	1,957	375	0	647	10	0	43	6	18	9	27	8	0	21	27	51
Sri Lanka	817	188		56	1	2	10	1	3		10	6		10		9
Sudan	969	218		308	46		57	2	39	29	6	27				183
Suriname	16	0	0	3	0	0	0	0	0	0	0	0	0	0	0	0
Sweden	741	195		203												
Syria	768	91	0	108	18		11	34	31	3		1		36	5	25
Tajikistan	417	31	9	15									12	17		
Tanzania	135	11	2													
Thailand	1,466	194		200	3	3	10	5	53	8	9	16	0	50	7	52
Togo	31	9	6	2												
Tunisia	444	116	0	186	41	0	19	6	78	6	45	29	5	48	3	11
Uganda	186	34	1	2												
Ukraine	1,860	328	0	469												
United Kingdom	6,830	1,518	0	10,969	813	15	234	27	1,559	277	3,418	76	0	148	95	2,842
United States	13,616	4,141		11,805	183	33	106	17	984	115	549	110	2,097	170	40	2,296
Uruguay	232	40	4	258			1		6		9			1	4	
Uzbekistan	1,491	169	13	126					10		6	6		19	2	
Venezuela	2,245	584		1,166	23	67	41	29	180	111	401	16	6	25	5	197
Vietnam	3,170	650	0	159	6	7	16	14	67	25	23	15	3	108	0	88
Zambia	83	20	27	5												
Zimbabwe	157	13	0	1	1											
TOTAL	**173,711**	**34,289**	**2,454**	**78,547**	**2,768**	**323**	**2,323**	**665**	**11,072**	**1,891**	**8,240**	**1,513**	**2,646**	**3,420**	**694**	**13,007**

TABLE 9. **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 identifed	Male	Percent male	Female	Percent female	Gender not known	Percent not known
Hemophilia A	**125**	173,711	155,139	**89**	5,229	**3**	10,224	**6**
Hemophilia B	**124**	34,289	29,938	**87**	1,734	**5**	1,798	**5**
Hemophilia type unknown	**84**	2,454	1,621	**66**	339	**14**	97	**4**
von Willebrand disease (VWD)	**111**	78,547	25,305	**32**	41,377	**53**	9,921	**13**
Factor I Deficiency	**75**	2,768	1,258	**45**	1,456	**53**	45	**2**
Factor II Deficiency	**67**	323	157	**49**	158	**49**	2	**1**
Factor V Deficiency	**75**	2,323	1,115	**48**	1,155	**50**	24	**1**
Factor V+VIII Deficiency	**71**	665	328	**49**	300	**45**	6	**1**
Factor VII Deficiency	**84**	11,072	5,438	**49**	5,378	**49**	106	**1**
Factor X Deficiency	**73**	1,891	990	**52**	875	**46**	6	**0**
Factor XI Deficiency	**75**	8,240	3,499	**42**	4,297	**52**	51	**1**
Factor XIII Deficiency	**79**	1,513	822	**54**	629	**42**	30	**2**
Bleeding disoder: type unknown	**58**	2,646	1,198	**45**	1,430	**54**	7	**0**
Platelet disorder: Glanzmann's Thrombasthenia	**71**	3,420	1,540	**45**	1,373	**40**	282	**8**
Platelet disorder: Bernard-Soulier Syndrome	**61**	694	294	**42**	325	**47**	62	**9**
Platelet Disorders: Other/Unknown	**64**	13,007	3,380	**26**	8,741	**67**	592	**5**

A woman who has ≤40% of the normal level of clotting factor (FVIII – hemophilia A, FIX – hemophilia B) is considered to be 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 10. **Number of inhibitor cases in Hemophilia A and B**

(109 countries reported number of inhibitors)

Patients with current clinically significant inhibitors refers to 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 active inhibitors	Hemophilia A new cases inhibitors	Hemophilia B active inhibitors	Hemophilia B new cases inhibitors
Afghanistan	2		0	
Albania	12	1	2	0
Algeria	55	9	0	0
Argentina	72	7	8	0
Armenia	8	8	1	1
Australia	63	6	3	0
Austria	19		1	
Azerbaijan	27	1		
Bahamas	1	0	0	0
Bangladesh		2		
Barbados	1	1	1	
Belarus	49	1	6	0
Belize	0		0	
Bolivia	4			
Bosnia-Herzegovina	5			
Botswana	3	1	0	
Brazil	496	61	18	3
Bulgaria	20		1	
Burkina Faso	1	0	0	0
Cambodia	4	2	0	0
Cameroon	13	0	2	0
Canada	45	8	2	0
Chile	24	1	3	1
China	211	112	12	8
Colombia	291	3	33	0
Costa Rica	22	0	0	0

	Hemophilia A active inhibitors	Hemophilia A new cases inhibitors	Hemophilia B active inhibitors	Hemophilia B new cases inhibitors
Cote d'Ivoire	4	0	0	0
Cuba	25	1	0	0
Czech Republic	24	3	2	0
Dominican Republic	19	2	6	
Ecuador	19	0	0	0
Egypt	234	92	2	0
El Salvador	6	0	0	0
Estonia	4	0	0	0
Finland	12	0	1	0
France	164	10	10	0
Georgia	9			
Germany	155		25	
Ghana		1		
Greece	20	2	3	0
Guatemala	15	15	0	0
Guyana	1			
Honduras	10	4	0	0
Hong Kong (China)	13	0	0	0
Hungary	21			
India	769		18	
Indonesia	65	1		
Iran	342	6	26	2
Iraq	193	14	7	2
Ireland	11	1	3	0
Israel	22	5	2	0
Italy	201	0	10	0
Jamaica	5	0	0	0
Japan	95		19	
Jordan	20		1	
Kenya	12	0	0	0
Korea, Republic of	50	3	4	0
Kyrgyzstan	6	3		
Latvia	3	0	1	0
Lebanon	11	1	0	
Lithuania	9			

	Hemophilia A active inhibitors	Hemophilia A new cases inhibitors	Hemophilia B active inhibitors	Hemophilia B new cases inhibitors
Macedonia	2	0	2	0
Madagascar	5	1	1	1
Malaysia	60	3	6	1
Mali	1	1	0	0
Mauritius	1	0	0	0
Mexico	251	0	17	0
Montenegro	1	0	0	0
Morocco	32	7		
Mozambique	2			
Myanmar	39	38	0	0
Nepal	20	5		
New Zealand	15	3	0	0
Nicaragua	5	3	0	0
Nigeria	0	0	0	0
Norway	14	4	0	0
Pakistan	27	8	1	0
Palestine	3	0		
Panama	3	0	0	0
Paraguay	1	1		
Philippines	22	10	2	1
Poland	146		4	
Qatar	1	1	0	0
Romania	80		1	
Russia	200		2	
Saudi Arabia	100	10	2	0
Senegal	9	2	0	0
Serbia	16	0	0	0
Singapore	5	0	0	0
Slovak Republic	6	1	1	0
Slovenia	3	0	0	0
South Africa	172		12	2
Sri Lanka	80	23		
Sudan	7	2		
Suriname	2	1		
Sweden	36	2	2	0

	Hemophilia A active inhibitors	Hemophilia A new cases inhibitors	Hemophilia B active inhibitors	Hemophilia B new cases inhibitors
Syria	37	0	1	0
Tajikistan	0	0	0	0
Thailand	77	14	4	1
Togo	1			
Tunisia	26	5	5	1
Uganda	2	2		
United Kingdom	226	29	12	0
United States	893		80	
Uruguay	9	0	2	0
Uzbekistan	40	1		
Venezuela	103	1	3	0
Vietnam	128	24	1	1
Zimbabwe	3	0	0	0
TOTAL	**6,929**	**590**	**394**	**25**

TABLE 11. **Age distribution: Hemophilia A**

(107 countries reported age data for hemophilia A)

	Hemophilia A	0–4	5–13	14–18	19–44	45+	Age not known
Afghanistan	402	4%	39%	31%	25%	1%	0%
Albania	190	4%	22%	13%	42%	20%	0%
Argentina	2,341	3%	16%	9%	46%	23%	3%
Armenia	230	3%	16%	4%	52%	14%	11%
Australia	2,152	5%	15%	7%	38%	35%	0%
Austria	658	3%	9%	8%	42%	39%	0%
Azerbaijan	1,357	3%	11%	36%	42%	7%	0%
Bahamas	7	0%	14%	14%	57%	14%	0%
Bangladesh	1,402	12%	33%	20%	31%	3%	0%
Barbados	22	0%	14%	5%	68%	14%	0%
Belarus	485	2%	12%	6%	45%	35%	0%
Belgium	1,007	2%	10%	9%	35%	44%	0%
Belize	13	8%	23%	31%	38%	0%	0%
Benin	73	4%	37%	5%	36%	3%	15%
Bolivia	117	12%	38%	19%	28%	3%	0%
Botswana	36	19%	22%	28%	28%	3%	0%
Brazil	10,558	4%	15%	10%	51%	20%	0%
Burkina Faso	53	30%	45%	6%	15%	0%	4%
Cambodia	161	6%	48%	18%	26%	0%	1%
Cameroon	133	22%	30%	27%	17%	4%	0%
Canada	3,018	3%	12%	7%	42%	35%	0%
Chile	1,506	4%	15%	11%	50%	22%	0%
China	16,158	6%	22%	10%	43%	13%	6%
Colombia	2,639	5%	8%	17%	56%	14%	0%
Costa Rica	183	3%	20%	9%	54%	11%	2%
Cote d'Ivoire	83	14%	35%	14%	33%	4%	0%
Cuba	415	4%	11%	8%	47%	29%	0%
Czech Republic	867	6%	12%	6%	31%	22%	23%
Dominican Republic	302	5%	21%	14%	42%	10%	9%
Egypt	4,885	11%	42%	5%	10%	3%	30%
El Salvador	105	15%	33%	21%	29%	2%	0%
Eritrea	54	2%	24%	20%	48%	2%	4%
Estonia	102	5%	9%	4%	62%	20%	1%
Ethiopia	145	9%	38%	14%	37%	2%	0%
Finland	169	7%	25%	20%	29%	16%	3%

	Hemophilia A	0–4	5–13	14–18	19–44	45+	Age not known
France	6,446	7%	15%	10%	40%	28%	0%
Georgia	270	3%	21%	6%	49%	21%	0%
Ghana	278	10%	45%	21%	14%	0%	10%
Greece	815	4%	8%	7%	46%	34%	0%
Guatemala	250	4%	17%	16%	44%	9%	10%
Guyana	13	0%	15%	8%	62%	15%	0%
Honduras	299	5%	27%	14%	43%	3%	7%
Hong Kong (China)	119	3%	24%	8%	55%	10%	1%
Hungary	914	4%	3%	5%	35%	42%	11%
India	17,606	2%	14%	10%	38%	8%	28%
Indonesia	2,035	11%	32%	16%	36%	3%	1%
Iran	5,208	4%	13%	8%	56%	19%	0%
Iraq	1,867	23%	40%	20%	15%	3%	0%
Ireland	715	14%	16%	8%	33%	29%	0%
Israel	608	10%	17%	10%	39%	24%	0%
Italy	4,135	3%	9%	6%	40%	42%	0%
Jamaica	43	5%	12%	21%	33%	26%	5%
Kenya	504	12%	29%	27%	14%	13%	4%
Korea, Republic of	1,721	5%	11%	8%	54%	23%	0%
Kyrgyzstan	343	7%	38%	14%	32%	8%	0%
Lebanon	169	10%	14%	14%	45%	16%	1%
Lesotho	24	4%	8%	63%	25%	0%	0%
Lithuania	152	0%	0%	0%	0%	0%	100%
Madagascar	70	11%	36%	11%	39%	3%	0%
Malawi	35	6%	31%	6%	20%	0%	37%
Malaysia	900	10%	19%	11%	41%	10%	10%
Maldives	14	14%	29%	7%	29%	21%	0%
Mali	128	20%	48%	16%	14%	0%	2%
Mauritania	61	7%	48%	21%	20%	5%	0%
Mauritius	74	0%	9%	12%	39%	28%	11%
Mexico	4,761	3%	20%	11%	42%	10%	14%
Mongolia	81	17%	40%	9%	30%	5%	0%
Montenegro	41	2%	15%	12%	32%	39%	0%
Morocco	183	11%	36%	8%	41%	4%	0%
Myanmar	464	22%	36%	13%	20%	3%	7%
Nepal	562	13%	19%	18%	36%	7%	6%
Netherlands	797	6%	10%	9%	32%	43%	0%
New Zealand	454	4%	11%	13%	36%	35%	0%

	Hemophilia A	0–4	5–13	14–18	19–44	45+	Age not known
Nicaragua	261	14%	32%	19%	34%	1%	0%
Nigeria	367	9%	34%	14%	22%	2%	20%
Norway	332	7%	17%	7%	38%	32%	0%
Pakistan	1,678	7%	34%	22%	34%	3%	0%
Panama	61	20%	74%	7%	0%	0%	0%
Paraguay	369	2%	5%	20%	38%	34%	0%
Philippines	1,124	4%	13%	13%	50%	8%	13%
Poland	2,442	1%	6%	4%	46%	42%	0%
Portugal	541	1%	9%	8%	41%	33%	8%
Qatar	47	13%	23%	28%	34%	2%	0%
Saudi Arabia	511	22%	37%	18%	23%	0%	0%
Senegal	208	9%	40%	17%	31%	2%	0%
Serbia	460	5%	11%	7%	48%	29%	0%
Singapore	213	4%	8%	8%	40%	40%	0%
Slovak Republic	528	4%	11%	5%	45%	35%	0%
Slovenia	217	5%	8%	4%	37%	46%	0%
South Africa	1,957	5%	17%	9%	42%	25%	2%
Sri Lanka	817	18%	18%	7%	23%	4%	31%
Sudan	969	20%	35%	14%	27%	3%	0%
Suriname	16	0%	13%	0%	50%	38%	0%
Sweden	741	5%	16%	9%	40%	29%	0%
Syria	768	15%	28%	16%	35%	5%	2%
Tajikistan	417	9%	31%	10%	45%	6%	0%
Thailand	1,466	27%	36%	7%	21%	9%	0%
Togo	31	16%	29%	10%	32%	6%	6%
Uganda	186	30%	43%	9%	17%	2%	0%
United Kingdom	6,830	6%	13%	6%	39%	36%	0%
United States	13,616	9%	24%	13%	34%	21%	0%
Uruguay	232	6%	13%	9%	48%	23%	0%
Uzbekistan	1,491	2%	17%	14%	58%	9%	0%
Venezuela	2,245	4%	13%	9%	39%	17%	17%
Vietnam	3,170	7%	23%	11%	47%	9%	3%
Zambia	83	10%	18%	20%	2%	4%	46%
Zimbabwe	157	4%	15%	16%	50%	6%	9%

TABLE 12. **Age distribution: Hemophilia B**

(104 countries reported age data for hemophilia B)

	Hemophilia B	0–4	5–13	14–18	19–44	45+	Age not known
Afghanistan	39	5%	13%	13%	49%	21%	0%
Albania	33	6%	9%	0%	64%	21%	0%
Argentina	370	4%	17%	10%	48%	19%	2%
Armenia	19	16%	16%	0%	53%	16%	0%
Australia	501	5%	12%	7%	40%	37%	0%
Austria	117	2%	10%	5%	45%	38%	0%
Azerbaijan	212	11%	9%	38%	33%	8%	0%
Bahamas	1	0%	0%	0%	100%	0%	0%
Bangladesh	267	15%	36%	20%	26%	3%	0%
Barbados	13	8%	0%	0%	77%	15%	0%
Belarus	106	0%	12%	5%	48%	35%	0%
Belgium	242	2%	8%	7%	33%	48%	0%
Belize	5	0%	0%	20%	80%	0%	0%
Benin	3	0%	33%	0%	33%	33%	0%
Bolivia	22	14%	23%	18%	45%	0%	0%
Botswana	7	0%	57%	0%	43%	0%	0%
Brazil	2095	5%	15%	10%	50%	20%	0%
Burkina Faso	22	18%	32%	23%	23%	0%	5%
Cambodia	27	4%	59%	11%	26%	0%	0%
Cameroon	23	52%	22%	17%	9%	0%	0%
Canada	669	1%	11%	7%	42%	39%	0%
Chile	173	5%	13%	8%	50%	24%	0%
China	2460	7%	21%	11%	42%	15%	5%
Colombia	591	5%	7%	15%	67%	7%	0%
Costa Rica	36	6%	17%	6%	58%	14%	0%
Cote d'Ivoire	13	23%	38%	15%	15%	8%	0%
Cuba	79	9%	13%	4%	43%	32%	0%
Czech Republic	136	6%	13%	7%	21%	29%	24%
Dominican Republic	37	3%	11%	3%	73%	5%	5%
Egypt	1143	8%	42%	2%	9%	1%	38%
El Salvador	12	25%	25%	17%	25%	8%	0%
Eritrea	6	0%	50%	0%	50%	0%	0%
Estonia	10	10%	30%	0%	30%	30%	0%
Ethiopia	28	11%	25%	11%	50%	4%	0%

	Hemophilia B	0–4	5–13	14–18	19–44	45+	Age not known
Finland	33	3%	27%	15%	33%	21%	0%
France	1498	7%	17%	11%	37%	28%	0%
Georgia	53	6%	19%	2%	49%	25%	0%
Ghana	16	13%	25%	25%	0%	0%	38%
Greece	184	4%	8%	4%	39%	45%	0%
Guatemala	34	3%	17%	17%	29%	3%	31%
Honduras	34	12%	24%	18%	38%	3%	6%
Hong Kong (China)	24	0%	21%	8%	38%	33%	0%
Hungary	230	2%	1%	4%	38%	43%	12%
India	2715	2%	13%	12%	42%	11%	21%
Indonesia	310	16%	38%	19%	24%	1%	3%
Iran	1109	3%	12%	8%	59%	18%	0%
Iraq	502	23%	40%	20%	13%	5%	0%
Ireland	243	4%	14%	11%	41%	30%	0%
Israel	104	14%	15%	18%	37%	15%	0%
Italy	886	3%	10%	9%	42%	37%	0%
Jamaica	4	0%	0%	25%	50%	25%	0%
Kenya	114	18%	25%	31%	21%	4%	2%
Korea, Republic of	427	4%	14%	11%	49%	22%	0%
Kyrgyzstan	40	8%	15%	15%	58%	5%	0%
Lebanon	47	6%	11%	23%	51%	9%	0%
Lithuania	24	0%	0%	0%	0%	0%	100%
Madagascar	57	16%	46%	16%	23%	0%	0%
Malawi	6	0%	50%	0%	17%	0%	33%
Malaysia	172	8%	17%	15%	41%	13%	6%
Maldives	4	50%	25%	25%	0%	0%	0%
Mali	13	62%	15%	8%	15%	0%	0%
Mauritania	15	7%	47%	20%	20%	7%	0%
Mauritius	13	8%	8%	23%	46%	8%	8%
Mexico	724	5%	19%	11%	44%	10%	12%
Mongolia	28	11%	39%	18%	25%	7%	0%
Montenegro	4	0%	0%	25%	50%	25%	0%
Morocco	34	10%	29%	23%	39%	0%	0%
Myanmar	76	45%	33%	7%	11%	4%	1%
Nepal	93	8%	30%	18%	27%	11%	6%
Netherlands	125	3%	13%	15%	31%	38%	0%
New Zealand	102	4%	8%	8%	33%	46%	0%

	Hemophilia B	0–4	5–13	14–18	19–44	45+	Age not known
Nicaragua	54	6%	11%	17%	15%	2%	50%
Nigeria	12	33%	33%	8%	8%	0%	17%
Norway	90	3%	18%	17%	28%	34%	0%
Pakistan	304	5%	23%	26%	43%	3%	0%
Panama	10	40%	50%	10%	0%	0%	0%
Paraguay	28	7%	18%	18%	36%	21%	0%
Philippines	193	4%	15%	13%	52%	7%	9%
Poland	428	2%	6%	7%	48%	36%	1%
Portugal	112	1%	9%	6%	39%	37%	8%
Qatar	6	33%	17%	50%	0%	0%	0%
Saudi Arabia	126	16%	41%	9%	34%	0%	0%
Senegal	30	13%	60%	17%	7%	3%	0%
Serbia	85	4%	18%	9%	47%	22%	0%
Singapore	46	2%	17%	7%	52%	22%	0%
Slovak Republic	79	6%	19%	8%	48%	19%	0%
Slovenia	30	3%	10%	3%	40%	43%	0%
South Africa	375	5%	21%	10%	39%	25%	1%
Sri Lanka	188	18%	21%	9%	3%	3%	46%
Sudan	218	19%	40%	17%	23%	1%	0%
Sweden	195	4%	14%	6%	38%	38%	0%
Syria	91	12%	29%	21%	35%	1%	2%
Tajikistan	31	10%	32%	19%	29%	10%	0%
Thailand	194	46%	20%	12%	13%	9%	0%
Togo	9	0%	33%	22%	11%	0%	33%
Uganda	34	24%	38%	12%	26%	0%	0%
United Kingdom	1518	6%	14%	6%	38%	36%	0%
United States	4141	9%	23%	12%	30%	26%	0%
Uruguay	40	5%	18%	13%	53%	13%	0%
Uzbekistan	169	3%	22%	9%	56%	9%	0%
Venezuela	584	3%	13%	7%	40%	21%	17%
Vietnam	650	5%	22%	11%	46%	13%	3%
Zambia	20	35%	5%	45%	15%	0%	0%
Zimbabwe	13	0%	15%	15%	38%	15%	15%

TABLE 13. **Age distribution: Hemophilia Type Unknown**

(34 countries reported age data)

	Hemophilia type unknown	0–4	5–13	14–18	19–44	45+	Age not known
Albania	1	0%	0%	0%	100%	0%	0%
Armenia	63	0%	6%	8%	70%	13%	3%
Bahamas	1	0%	100%	0%	0%	0%	0%
Bangladesh	6	0%	0%	100%	0%	0%	0%
Belgium	9	0%	0%	0%	11%	78%	11%
Benin	7	0%	0%	0%	0%	0%	100%
Cambodia	1	0%	0%	0%	100%	0%	0%
Chile	65	0%	0%	0%	0%	100%	0%
China	94	4%	18%	19%	39%	13%	6%
Dominican Republic	29	0%	28%	3%	48%	10%	10%
Ethiopia	155	19%	37%	19%	25%	0%	0%
Finland	54	0%	0%	0%	56%	44%	0%
Ghana	6	100%	0%	0%	0%	0%	0%
Guatemala	40	2%	6%	2%	2%	0%	88%
Honduras	27	0%	22%	19%	22%	0%	37%
Hong Kong (China)	32	0%	0%	25%	75%	0%	0%
India	457	1%	7%	11%	33%	9%	39%
Korea, Republic of	175	2%	11%	10%	50%	26%	0%
Lithuania	1	0%	0%	0%	0%	0%	100%
Malaysia	3	100%	0%	0%	0%	0%	0%
Maldives	1	100%	0%	0%	0%	0%	0%
Mexico	329	1%	8%	5%	21%	6%	58%
Morocco	0	0%	0%	0%	100%	0%	0%
Myanmar	7	29%	71%	0%	0%	0%	0%
Nigeria	18	50%	11%	0%	17%	0%	22%
Philippines	210	2%	12%	11%	43%	5%	26%
Portugal	52	0%	0%	8%	21%	29%	42%
Syria	0	50%	25%	25%	0%	0%	0%
Tajikistan	9	11%	56%	0%	0%	33%	0%
Togo	6	0%	67%	0%	17%	0%	17%
Uganda	1	0%	0%	100%	0%	0%	0%
Uruguay	4	0%	25%	25%	50%	0%	0%
Uzbekistan	13	8%	54%	0%	0%	38%	0%
Zambia	27	19%	0%	7%	74%	0%	0%

TABLE 14. **Age distribution: VWD**

(93 countries reported age data)

	Total number of patients	0–4	5–13	14–18	19–44	45+	Age not known
Albania	6	0%	17%	0%	67%	17%	0%
Argentina	397	0%	1%	3%	44%	37%	14%
Armenia	28	4%	7%	14%	68%	7%	0%
Australia	2,146	1%	9%	6%	44%	39%	0%
Azerbaijan	214	4%	7%	26%	30%	34%	0%
Bahamas	2	0%	0%	0%	100%	0%	0%
Bangladesh	2	50%	0%	0%	50%	0%	0%
Barbados	1	0%	0%	0%	100%	0%	0%
Belgium	2,056	1%	14%	10%	42%	34%	1%
Bolivia	2	0%	100%	0%	0%	0%	0%
Botswana	5	0%	60%	40%	0%	0%	0%
Brazil	8,957	1%	10%	9%	53%	27%	0%
Cambodia	6	0%	67%	33%	0%	0%	0%
Cameroon	3	0%	0%	33%	33%	33%	0%
Canada	4,321	1%	6%	6%	48%	36%	4%
Chile	452	0%	0%	0%	0%	0%	100%
China	149	7%	26%	9%	31%	23%	5%
Colombia	2,770	1%	22%	12%	61%	5%	0%
Costa Rica	87	0%	1%	8%	51%	38%	2%
Cote d'Ivoire	3	33%	0%	0%	33%	33%	0%
Cuba	386	1%	11%	23%	45%	22%	0%
Czech Republic	760	1%	8%	7%	33%	31%	20%
Dominican Republic	39	5%	8%	10%	62%	10%	5%
Egypt	583	7%	45%	3%	1%	2%	41%
El Salvador	2	50%	0%	50%	0%	0%	0%
Estonia	113	2%	19%	10%	44%	17%	8%
Finland	547	0%	8%	12%	45%	34%	0%
France	2,479	6%	14%	11%	38%	31%	0%
Georgia	39	5%	23%	13%	36%	23%	0%
Ghana	8	0%	100%	0%	0%	0%	0%
Greece	1,100	2%	14%	11%	44%	29%	0%
Guatemala	23	4%	13%	13%	26%	17%	26%

	Total number of patients	0–4	5–13	14–18	19–44	45+	Age not known
Honduras	18	11%	22%	11%	44%	0%	11%
Hong Kong (China)	1	0%	0%	0%	0%	100%	0%
Hungary	1,471	0%	2%	6%	41%	46%	5%
India	676	3%	16%	13%	45%	7%	16%
Indonesia	17	12%	29%	12%	29%	12%	6%
Iran	1,644	5%	17%	11%	52%	15%	0%
Iraq	480	18%	29%	38%	13%	3%	0%
Ireland	1,693	9%	17%	7%	42%	25%	0%
Israel	168	0%	0%	0%	0%	0%	100%
Italy	2,854	1%	5%	6%	41%	47%	0%
Jamaica	2	0%	0%	0%	0%	0%	100%
Kenya	30	17%	27%	37%	17%	3%	0%
Korea, Republic of	135	1%	7%	11%	59%	21%	0%
Kyrgyzstan	16	6%	13%	31%	50%	0%	0%
Lebanon	159	6%	18%	9%	51%	11%	4%
Lithuania	305	0%	0%	0%	0%	0%	100%
Madagascar	2	0%	0%	0%	100%	0%	0%
Malaysia	132	1%	11%	7%	60%	7%	15%
Mali	20	20%	20%	20%	35%	5%	0%
Mauritius	1	0%	100%	0%	0%	0%	0%
Mexico	328	2%	16%	11%	38%	8%	27%
Mongolia	13	0%	23%	23%	38%	15%	0%
Montenegro	3	0%	0%	33%	67%	0%	0%
Morocco	22	5%	18%	55%	9%	14%	0%
Myanmar	19	21%	58%	5%	0%	0%	16%
Nepal	5	0%	0%	40%	0%	60%	0%
Netherlands	140	4%	20%	7%	31%	37%	0%
New Zealand	405	1%	15%	3%	19%	61%	0%
Nicaragua	89	4%	29%	19%	39%	8%	0%
Nigeria	7	0%	57%	14%	14%	0%	14%
Pakistan	294	4%	31%	14%	49%	2%	0%
Panama	128	3%	65%	32%	0%	0%	0%
Paraguay	1	0%	0%	0%	100%	0%	0%
Philippines	43	0%	5%	9%	28%	7%	51%
Poland	1,980	1%	14%	8%	50%	26%	1%

	Total number of patients	0–4	5–13	14–18	19–44	45+	Age not known
Portugal	51	2%	4%	4%	37%	49%	4%
Qatar	37	14%	24%	49%	8%	5%	0%
Saudi Arabia	241	17%	34%	24%	24%	0%	0%
Senegal	10	40%	30%	20%	10%	0%	0%
Serbia	301	2%	8%	6%	52%	33%	0%
Singapore	88	0%	11%	2%	40%	47%	0%
Slovak Republic	696	1%	7%	6%	54%	33%	0%
Slovenia	186	1%	5%	9%	54%	32%	0%
South Africa	647	0%	6%	8%	43%	40%	4%
Sri Lanka	56	11%	21%	4%	7%	11%	46%
Sudan	308	19%	34%	18%	26%	3%	0%
Suriname	3	0%	33%	0%	33%	33%	0%
Sweden	203	3%	9%	4%	43%	40%	0%
Syria	108	13%	30%	12%	39%	6%	0%
Tajikistan	15	0%	0%	0%	100%	0%	0%
Thailand	200	0%	0%	0%	0%	0%	100%
Togo	2	0%	100%	0%	0%	0%	0%
Uganda	2	0%	0%	50%	0%	50%	0%
United Kingdom	10,969	3%	11%	6%	41%	39%	0%
United States	11,805	6%	31%	22%	24%	17%	0%
Uruguay	258	0%	61%	1%	3%	1%	33%
Uzbekistan	126	1%	23%	15%	50%	11%	0%
Venezuela	1,166	1%	13%	11%	39%	17%	18%
Vietnam	159	3%	25%	14%	41%	13%	4%
Zambia	5	0%	0%	80%	0%	20%	0%
Zimbabwe	1	0%	0%	0%	100%	0%	0%

TABLE 15. **HIV and HCV infection**

(91 countries reported HIV and/or 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
Albania	1	0	0	33	0	0			
Algeria	2	0		24	15	2	9	5	
Argentina	55	0	0	600	20	0			
Armenia	0	1	0	71	0	0	15	0	0
Austria	46			196					
Azerbaijan				582	65	49	23	61	22
Bahamas	0	0	0	0	0	0	0	0	0
Barbados	0			2					
Belarus	0	0	0						
Benin	0	0	0	0	0	0	0	0	0
Botswana	1	0							
Cameroon	0	0	0	0	0	0	0	0	0
Chile	5	0	0						
China	61	0	1	201	2	0			
Colombia	12	2	0	192	50	0	71	6	0
Costa Rica	6	0	0	48	0	1	5	0	0
Cote d'Ivoire	1	0	0	1	0	0	1	0	0
Cuba	4	0	0	137	5	1			
Czech Republic	3	0	0	195	3	1	61	1	0
Denmark	23								
Dominican Republic	0	0	0	27	0	8	20	0	8
Ecuador	10	10	0	18	3	0	18	3	
Eritrea	0								
Estonia	1	0	0	28	1				
France	532	17	4	2,059	176	46	41	6	0
Georgia	0	0	0	81	7	0			
Germany	367								

	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
Ghana	0	0	0	0	0	0	0	0	0
Greece	49	2	0	285	25	7	33	3	1
Guatemala							2	0	0
Honduras	0	1	0						
Hong Kong (China)	0	0	0						
Hungary	10			400	108				
India	114								
Iran	24	1	1	1,069	155	152	116	17	17
Iraq	1	0	0	306	64	6			
Ireland	32			165	10	3	5	0	0
Israel	24	0							
Italy	249	9	0						
Jamaica	1	0	0	1	0	0			
Japan	738	2	0	1,541	99	65	941	61	41
Jordan	0								
Kenya	23	2	0						
Korea, Republic of	18			552	2	6	85	0	1
Kyrgyzstan	0	0	0	35					
Latvia	0	0	0						
Lebanon	0	0	0						
Macedonia	0	0	0						
Madagascar	0	0	0	1	0	0	0	0	0
Malawi	0	0	0	0	0	0	0	0	0
Malaysia	3	0	0	33	2	0	18	2	0
Mali	0	0	0						
Mauritius	0	0	0	8	0	1	8	0	1
Mexico	45	3	0	275	6	0			
Montenegro	0	0	0	3	0	0	1	0	0
Morocco	0	0	0	4	0	0	1	0	0
Mozambique	2			1					
Myanmar	1	0	0	6	0	0	0	0	0
Nepal	1			9					
New Zealand	6	0	0	7	0	0	2	0	0
Nicaragua	1	0	0	27	0	0	0	0	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
Norway	6	0	0						
Pakistan	16	0	2	202	46	9	202	46	9
Palestine	0	0	0	5	0	0	0	0	0
Paraguay	0	0	0	0	0	0	0	0	0
Poland	3	0	0						
Qatar	0	0	0	0	0	0	0	0	0
Saudi Arabia	0			0			0		
Senegal	0	0		0	1		0	0	
Serbia	7	2	0	115	5	2			
Singapore	0	0	0	69	2	0	0	0	0
Slovak Republic	0	0	0	130	22	16	22	2	0
Slovenia	7	0	0	96	6	3	0	0	0
South Africa	61	3	0	216	3	2			
Sri Lanka				1					
Sudan	2	1	1	42					
Suriname	0	0							
Sweden	16	0	0						
Syria	0	0	0	71	6	0	0	0	0
Thailand	11	0		66	1		1		
Togo	0								
Tunisia	10	0		76			2		
Uganda	1	1							
United Kingdom	269	4	0	1,588	167	26	179	24	2
United States	882	13	5				1,781	86	49
Uruguay				6			6		
Uzbekistan	11			190	10				
Venezuela	83	9	1	320	24		60	8	
Vietnam	4	0	0	349	2	46	349	2	0
Zambia	1	0	0	0	0	0	0	0	0
Zimbabwe	4	0	0	3	0	0			

** Hepatitis C antibody positive at any time*

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

TABLE 16. **Percentage of patients on prophylaxis**

(99 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
Argentina	80	Estimate	10	Estimate
Armenia	30	Estimate	15	Estimate
Australia	92	Estimate	77	Estimate
Austria	88	Precise	70	Precise
Bahamas	0	Precise	0	Precise
Barbados	2	Precise	1	Precise
Belarus	90	Estimate	2	Estimate
Belgium	90	Estimate	75	Estimate
Bosnia-Herzegovina	90	Estimate		
Botswana	100	Precise	90	Estimate
Brazil	92	Precise	56	Precise
Bulgaria	95	Estimate	5	Estimate
Burkina Faso	24	Precise	10	Precise
Cambodia	5	Estimate	0	Estimate
Canada	72	Estimate	74	Estimate
Chile	100	Estimate	50	Estimate
China	15	Estimate	7	Estimate
Colombia	95	Precise	80	Precise
Costa Rica	39	Precise	17	Precise
Cote d'Ivoire	25	Precise	0	Precise
Cuba	13	Precise	0	Precise
Czech Republic	91	Precise	59	Precise
Dominican Republic	40	Precise	0	Precise
Ecuador	100	Estimate	80	Estimate
Egypt	4	Estimate	1	Estimate
El Salvador	60	Estimate	0	Precise
Eritrea	90	Estimate	30	Estimate
Estonia	100	Precise	20	Precise
Ethiopia	0	Precise	0	Precise
Finland	95	Estimate		
France	77	Precise	52	Precise
Georgia	32	Estimate		

	Percent under 18 on prophylaxis	Precise or estimate	Percent over 18 on prophylaxis	Precise or estimate
Germany	100	Estimate		
Ghana	80	Estimate	50	Estimate
Greece	92	Precise	42	Estimate
Guatemala	17	Estimate		
Guyana	3	Estimate	3	Estimate
Hong Kong (China)	100	Precise	100	Precise
Hungary	100	Precise	70	Estimate
India	9	Estimate	4	Estimate
Indonesia	0	Precise	0	Precise
Iran	45	Precise	25	Precise
Iraq	100	Precise	28	Precise
Ireland	96	Estimate	95	Estimate
Israel	95	Estimate	65	Estimate
Japan	90	Estimate	90	Estimate
Jordan	12	Estimate	10	Estimate
Kenya	10	Precise	5	Precise
Kyrgyzstan	1	Estimate	0	Precise
Lebanon	23	Estimate	10	Estimate
Lesotho	0	Precise	0	Precise
Lithuania	100	Precise	40	Estimate
Macedonia	100	Precise	30	Estimate
Madagascar	10	Estimate	10	Estimate
Malawi	20	Estimate	15	Estimate
Malaysia	85	Estimate	65	Estimate
Maldives	0	Precise	0	Precise
Mali	80	Estimate	10	Estimate
Mauritania	5	Precise	1	Estimate
Mauritius	100	Precise	96	Precise
Mongolia	100	Precise	100	Precise
Montenegro	89	Precise	50	Precise
Morocco	33	Estimate	7	Estimate
Mozambique	1	Estimate	20	Estimate
Myanmar	30	Estimate	4	Precise
Netherlands	100	Estimate	90	Estimate
New Zealand	99	Estimate	60	Estimate
Nicaragua	0	Precise	0	Precise
Norway	95	Estimate	70	Estimate

	Percent under 18 on prophylaxis	Precise or estimate	Percent over 18 on prophylaxis	Precise or estimate
Pakistan	60	Precise	1	Precise
Palestine	65	Estimate	25	Estimate
Panama	100	Precise	100	Precise
Paraguay	10	Estimate	1	Estimate
Philippines	2	Precise	0	Precise
Poland	80	Estimate	60	Estimate
Qatar	100	Estimate	40	Estimate
Romania	100	Precise	35	Precise
Russia	95	Estimate	65	Estimate
Senegal	17	Precise	0	Precise
Serbia	90	Precise	35	Precise
Singapore	88	Precise	54	Precise
Slovak Republic	95	Precise	45	Precise
Slovenia	87	Precise	78	Precise
South Africa	35	Estimate	25	Estimate
Sri Lanka	31	Precise	33	Precise
Sudan	0	Precise	0	Precise
Suriname	50	Precise	0	Precise
Sweden	95	Estimate	90	Estimate
Syria	0	Precise	0	Precise
Thailand	20	Estimate	5	Estimate
Togo	0	Estimate	0	Estimate
Uganda	0	Estimate	0	Estimate
Ukraine	30	Estimate	5	Estimate
United Kingdom	87	Estimate	78	Estimate
Uruguay	72	Estimate	10	Estimate
Uzbekistan	0	Precise	0	Precise
Venezuela	30	Estimate	20	Estimate
Zambia	29	Precise	29	Precise
Zimbabwe	5	Estimate	3	Estimate

TABLE 17. **Use of Factor Concentrates in 2018: Factor VIII**

(111 countries reported Factor VIII data)

The quantities of factor VIII in this chart are as reported to the WFH and are not independently verified except when the WFH provided humanitarian aid products. In some cases the numbers reported may be based on an estimate or from one region or certain treatment centres. Some countries report the amount of factor concentrate consumed in the year 2018 while others report the amount purchased. Factor VIII IU calculated includes plasma derived, recombinant, extended half life products and humanitarian aid. 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.

	Factor VIII total IU	Factor VIII plasma derived	Factor VIII recombinant	Factor VIII recombinant - extended half life	Total percent plasma derived	Total percent recombinant	Total percent extended half life	Factor VIII humanitarian aid total	Factor VIII WFH humanitarian aid - standard half life	Factor VIII WFH humanitarian aid - extended half life	Factor VIII per capita	Factor VIII per capita without humanitarian aid
Afghanistan	1,781,500	0	0	0	0	0	0	1,781,500	339,500	0	0.048	0
Albania	6,500,000	3,500,000	0	0	100	0	0	3,000,000			2.268	1.221
Algeria	83,123,976	17,635,991	65,478,985	No data	21	79	0				1.968	1.968
Argentina	218,000,000	129,000,000	89,000,000	0	59	41	0	0			4.899	4.899
Armenia	1,774,250	500,000	0	0	100	0	0	1,274,250	861,750	412,500	0.601	0.169
Australia	169,349,922	20,419,502	144,906,170	4,024,250	12	86	2	0			6.776	6.776
Azerbaijan	5,000,000	5,000,000	No data	No data	100	0	0				0.503	0.503
Bahamas	600,000	0	0	0	0	0	0	600,000			1.556	0
Bangladesh	3,276,460	No data	No data	No data				3,276,460	1,676,460	1,600,000	0.02	0
Barbados	150,000	No data	No data	No data				150,000	150,000	0	0.523	0
Belarus	36,250,000	36,250,000	0	0	100	0	0	0			3.822	3.822
Belize	297,314	No data	No data	No data				297,314	101,750	50,000	0.776	0
Benin	100,000	No data	No data	No data				100,000	100,000	0	0.009	0
Bolivia	3,738,000	No data	No data	No data	0	0	0	2,123,000	108,000	400,000	0.329	0.142
Bosnia-Herzegovina	10,433,000	6,230,000	4,203,000	No data	60	40	0				3.139	3.139
Brazil	846,874,500	233,377,500	613,497,000	0	28	72	0	0			4.043	4.043
Bulgaria	21,792,100	16,789,100	4,915,000	88,000	77	23	0				3.102	3.102
Burkina Faso	456,650	0	0	0	0	0	0	456,650	406,650	50,000	0.023	0
Cambodia	874,400	No data	No data	No data				874,400	574,400	300,000	0.054	0
Cameroon	781,420	No data	No data	No data				781,420	531,420	250,000	0.031	0

	Factor VIII total IU	Factor VIII plasma derived	Factor VIII recombinant	Factor VIII recombinant - extended half life	Total percent plasma derived	Total percent recombinant	Total percent extended half life	Factor VIII humanitarian aid total	Factor VIII WFH humanitarian aid - standard half life	Factor VIII WFH humanitarian aid - extended half life	Factor VIII per capita	Factor VIII per capita without humanitarian aid
Canada	302,051,565	44,425,140	204,168,836	53,457,589	15	68	18	0			8.151	8.151
Chile	72,000,000	72,000,000	0	0	100	0	0	0			3.844	3.844
China	35,714,610	17,702,860	18,011,750	No data	50	50	0				0.026	0.026
Colombia	247,542,000	97,766,000	131,694,000	18,082,000	39	53	7	0			4.986	4.986
Costa Rica	15,784,250	15,784,250	0	0	100	0	0	0			3.157	3.157
Cote d'Ivoire	681,600	0	0	0	0	0	0	681,600			0.027	0
Cuba	8,100,000	7,000,000	100,000	0	99	1	0	1,000,000			0.714	0.626
Czech Republic	65,774,559	23,464,244	42,310,315	0	36	64	0	0			6.19	6.19
Dominican Republic	3,719,000	2,500,000	No data	No data	100	0	0	1,219,000	504,000	600,000	0.35	0.235
Ecuador	44,000,000	35,000,000	9,000,000	No data	80	20	0	0			2.575	2.575
Egypt	72,975,000	54,500,000	10,000,000	0	84	16	0	8,475,000			0.741	0.655
El Salvador	2,106,830	No data	No data	No data				2,106,830	1,356,830	750,000	0.328	0
Eritrea	696,300	0	0	0	0	0	0	696,300	508,800	187,500	0.119	0
Estonia	4,922,500	2,200,000	2,722,500	No data	45	55	0	0			3.727	3.727
Ethiopia	1,161,000	0	0	0	0	0	0	1,161,000	1,086,000	75,000	0.011	0
Finland	44,416,450	4,330,200	34,163,250	5,923,000	10	77	13	0			8.049	8.049
Georgia	12,550,000	12,550,000	No data	No data	100	0	0				3.364	3.364
Germany	630,238,544	206,536,967	No data	No data	33	0	0	0			7.6	7.6
Ghana	2,224,000	No data	No data	No data				2,224,000	1,024,000	1,200,000	0.075	0
Greece	53,076,500	8,033,000	36,267,000	8,776,500	15	68	17	0			4.948	4.948
Guatemala	5,946,126	0	0	0	0	0	0	106,626			0.345	0.339
Guyana	262,750	No data	No data	No data				262,750	262,750	0	0.337	0
Honduras	8,185,360	7,456,000	0	0	100	0	0	729,360	529,360	200,000	0.854	0.778
Hungary	144,510,750	80,500,000	64,010,750	0	56	44	0				14.793	14.793
India	311,722,250	157,500,000	105,000,000	0	60	40	0	49,222,250	22,884,750	26,337,500	0.23	0.194
Indonesia	2,287,000	No data	No data	No data				2,287,000	712,000	1,575,000	0.009	0
Iran	146,149,250	72,799,250	73,350,000	No data	50	50	0	0			1.787	1.787
Iraq	45,000,000	0	45,000,000	0	0	100	0	0			1.171	1.171
Ireland	52,193,850	2,932,500	8,234,600	41,026,750	6	16	79	0			10.754	10.754
Jamaica	1,043,100	No data	No data	No data				1,043,100	855,600	187,500	0.355	0
Japan	772,842,000	62,516,000	No data	No data	8	0	0	0			6.108	6.108
Jordan	9,892,954	5,840,000	1,460,000	0	80	20	0	2,592,954	742,954	1,850,000	0.994	0.733

	Factor VIII total IU	Factor VIII plasma derived	Factor VIII recombinant	Factor VIII recombinant - extended half life	Total percent plasma derived	Total percent recombinant	Total percent extended half life	Factor VIII humanitarian aid total	Factor VIII WFH humanitarian aid - standard half life	Factor VIII WFH humanitarian aid - extended half life	Factor VIII per capita	Factor VIII per capita without humanitarian aid
Kenya	4,100,000	0	0	0	0	0	0	4,100,000	398,000	3,275,000	0.08	0
Korea, Republic of	271,356,000	52,948,000	218,408,000	No data	20	80	0				5.255	5.255
Kyrgyzstan	4,488,902	497,500	1,198,000	0	29	71	0	2,793,402	1,843,402	950,000	0.711	0.268
Latvia	8,511,750	5,162,500	3,349,250	0	61	39	0	0			4.418	4.418
Lebanon	1,086,000	No data	No data	No data				1,086,000	14,500	0	0.159	0
Lithuania	22,084,750	9,290,000	12,794,750	No data	42	58	0				7.917	7.917
Macedonia	5,372,000	4,936,000	36,000	0	99	1	0	400,000			2.579	2.387
Madagascar	1,144,500	0	0	0	0	0	0	1,144,500	494,500	650,000	0.044	0
Malawi	933,900	0	0	0	0	0	0	933,900	156,000	425,000	0.051	0
Malaysia	46,594,250	43,601,500	2,992,750	0	94	6	0	0			1.478	1.478
Maldives	86,250	No data	No data	No data				86,250	50,000	0	0.167	0
Mali	1,424,500	0	0	0	0	0	0	1,424,500	599,500	825,000	0.075	0
Mauritania	1,163,750	267,000	0	0	100	0	0	896,750	596,750	300,000	0.264	0.061
Mauritius	4,150,000	4,150,000	0	0	100	0	0	0			3.28	3.28
Mongolia	4,831,000	No data	3,137,500	402,000	0	89	11	1,291,500	604,000	587,500	1.524	1.116
Montenegro	1,650,000	1,650,000	0	0	100	0	0	0			2.651	2.651
Morocco	6,170,200	72,500	1,256,500	No data	4	65	0	4,244,000	2,644,000	1,600,000	0.171	0.053
Mozambique	888,066	No data	No data	No data	0	0	0				0.03	0.03
Myanmar	6,859,050	No data	No data	No data				6,859,050	5,613,100	550,000	0.128	0
Nepal	1,728,500	No data	No data	No data				1,728,500	1,253,500	475,000	0.062	0
Nicaragua	1,506,400	0	0	0	0	0	0	1,506,400	856,400	650,000	0.233	0
Nigeria	5,674,000	0	0	0	0	0	0	5,674,000	1,260,000	3,687,500	0.029	0
Norway	37,475,250	1,696,000	29,484,250	6,295,000	5	79	17	0			7.052	7.052
Pakistan	8,078,234	978,234	0	0	100	0	0	7,100,000	3,760,000	2,750,000	0.038	0.005
Palestine	8,052,500	No data	No data	No data	0	0	0	756,000	756,000	0	1.762	1.597
Panama	1,461,500	1,059,750	401,750	No data	73	27	0	0			0.35	0.35
Paraguay	1,022,000	No data	No data	No data	0	0	0	926,000	126,000	800,000	0.147	0.014
Philippines	6,424,740	2,713,500	0	0	100	0	0	3,711,240	2,923,740	787,500	0.06	0.025
Poland	278,143,750	263,586,750	14,557,000	0	95	5	0	0			7.324	7.324
Portugal	46,275,750	13,037,000	32,762,250	476,500	28	71	1				4.501	4.501
Qatar	14,500,000	0	No data	No data	0	0	0	0			5.213	5.213
Romania	52,903,850	32,493,600	20,410,250	0	61	39	0				2.717	2.717

	Factor VIII total IU	Factor VIII plasma derived	Factor VIII recombinant	Factor VIII recombinant - extended half life	Total percent plasma derived	Total percent recombinant	Total percent extended half life	Factor VIII humanitarian aid total	Factor VIII WFH humanitarian aid - standard half life	Factor VIII WFH humanitarian aid - extended half life	Factor VIII per capita	Factor VIII per capita without humanitarian aid
Russia	1,191,663,849	630,142,484	561,521,365	0	53	47	0	0			8.248	8.248
Saudi Arabia	92,575,000	36,225,000	41,350,000	15,000,000	39	45	16	0			2.747	2.747
Senegal	993,500	0	0	0	0	0	0	993,500	893,500	100,000	0.063	0
Serbia	24,854,500	10,942,000	13,912,500	0	44	56	0				3.56	3.56
Singapore	11,217,750	4,813,000	6,404,750	No data	43	57	0	0			1.989	1.989
Slovak Republic	46,000,000	34,550,000	9,100,000	2,350,000	75	20	5	0			8.445	8.445
Slovenia	17,273,500	1,222,000	14,046,000	2,005,500	7	81	12	0			8.355	8.355
South Africa	70,174,100	67,735,100	2,439,000	No data	97	3	0	0			1.215	1.215
Sri Lanka	18,950,000	No data	No data	No data	0	0	0	10,175,000	2,388,000	7,050,000	0.874	0.405
Sudan	7,950,000	7,950,000	0	0	100	0	0	0			0.19	0.19
Sweden	103,198,750	1,251,000	84,112,500	17,835,250	1	82	17	0			10.134	10.134
Syria	14,798,500	14,227,500	0	0	100	0	0	571,000			0.875	0.842
Tajikistan	198,000	No data	No data	No data				198,000	198,000	0	0.022	0
Tanzania	600,000	No data	No data	No data				600,000	318,630	225,000	0.011	0
Thailand	28,973,500	19,378,500	6,120,000	No data	76	24	0	3,475,000	0	3,475,000	0.417	0.367
Togo	135,000	No data	No data	No data				135,000	135,000	0	0.017	0
Tunisia	17,823,500	9,980,500	7,843,000	0	56	44	0	0			1.541	1.541
Uganda	1,721,823	No data	No data	No data				1,721,823	460,500	1,200,000	0.04	0
Ukraine	111,528,608	25,769,304	29,995,000	0	46	54	0	55,764,304			2.499	1.25
United Kingdom	586,797,061	15,742,605	477,291,792	93,762,664	3	81	16	0			8.825	8.825
United States	3,260,000,000	270,000,000	2,390,000,000	600,000,000	8	73	18				9.964	9.964
Uruguay	9,100,000	No data	0	0	0	0	0	0			2.638	2.638
Uzbekistan	34,030,000	4,960,000	1,300,000	No data	79	21	0	27,770,000	1,477,000	1,300,000	1.033	0.19
Venezuela	32,559,250	0	0	0	0	0	0	32,559,250	19,380,750	5,625,000	1.128	0
Vietnam	22,006,750	21,679,750	No data	No data	100	0	0	327,000			0.23	0.227
Zambia	690,000	No data	No data	No data				690,000	690,000	0	0.04	0
Zimbabwe	527,500	0	0	0	0	0	0	527,500	527,500	0	0.037	0
TOTAL	**11,094,740,373**	**3,076,747,081**	**5,693,717,313**	**870,840,003**				**270,692,133**	**85,735,246**	**73,312,500**		

TABLE 18. **Use of Factor Concentrates in 2018: Factor IX**

(105 countries reported Factor IX data.)

The quantities of factor IX in this chart are as reported to the WFH and are not independently verified except when the WFH provided humanitarian aid products. In some cases the numbers reported may be based on an estimate or from one region or certain treatment centres. Some countries report the amount of factor concentrate consumed in the year 2018 while others report the amount purchased. Factor IX Total IU calculated includes plasma derived, recombinant, extended half life products and humanitarian aid. 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.

	Factor IX total IU	Factor IX plasma derived	Factor IX recombinant	Factor IX recombinant, extended half life	Total percent plasma derived	Total percent recombinant	Total percent extended half life	Factor IX humanitarian aid total	Factor IX WFH humanitarian aid - conventional	Factor IX WFH humanitarian aid - extended half-life	Factor IX per capita	Factor IX per capital without humanitarian aid
Afghanistan	300,000	0	0	0	0	0	0	300,000	0	0	0.008	0.000
Albania	400,000	400,000	0	0	100	0	0	0			0.140	0.140
Algeria	18,981,200	18,981,200	No data	No data	100	0	0				0.449	0.449
Argentina	12,000,000	10,000,000	2,000,000	0	83	17	0	0			0.270	0.270
Armenia	350,000	0	0	0	0	0	0	350,000	0	350,000	0.119	0.000
Australia	28,748,125	96,000	27,120,375	1,531,750	0	94	5	0			1.150	1.150
Azerbaijan	2,000,000	2,000,000	No data	No data	100	0	0				0.201	0.201
Bangladesh	650,000	No data	No data	No data				650,000	0	650,000	0.004	0.000
Belarus	5,200,000	5,200,000	0	0	100	0	0	0			0.548	0.548
Belize	308,000	No data	No data	No data				308,000	0	50,000	0.804	0.000
Benin	22,000	No data	No data	No data				22,000	22,000	0	0.002	0.000
Bolivia	330,000	No data	No data	No data	0	0	0	185,000	40,000	0	0.029	0.013
Bosnia-Herzegovina	2,001,000	1,533,000	468,000	No data	77	23	0				0.602	0.602
Brazil	132,319,500	132,319,500	0	0	100	0	0	0			0.632	0.632
Bulgaria	2,532,700	1,889,200	643,500	No data	75	25	0				0.361	0.361
Burkina Faso	214,000	No data	No data	No data				214,000	32,500	50,000	0.011	0.000
Cambodia	312,500	No data	No data	No data				312,500	0	312,500	0.019	0.000
Cameroon	50,000	No data	No data	No data				50,000	0	50,000	0.002	0.000
Canada	58,609,096	3,728,656	39,677,971	15,202,469	6	68	26	0			1.582	1.582
Chile	14,000,000	14,000,000	0	0	100	0	0	0			0.748	0.748
China	3,898,230	3,874,480	23,750	No data	99	1	0				0.003	0.003
Colombia	39,942,000	18,673,000	20,197,000	1,000,000	47	51	3	72,000			0.804	0.803
Costa Rica	4,093,500	4,093,500	0	0	100	0	0	0			0.819	0.819

	Factor IX total IU	Factor IX plasma derived	Factor IX recombinant	Factor IX recombinant, extended half life	Total percent plasma derived	Total percent recombinant	Total percent extended half life	Factor IX humanitarian aid total	Factor IX WFH humanitarian aid - conventional	Factor IX WFH humanitarian aid - extended half-life	Factor IX per capita	Factor IX per capital without humanitarian aid
Cote d'Ivoire	100,000	0	0	0	0	0	0	100,000			0.004	0.000
Cuba	550,000	550,000	0	0	100	0	0	0			0.049	0.049
Czech Republic	7,008,709	2,993,717	3,555,476	459,516	43	51	7	0			0.660	0.660
Dominican Republic	885,000	340,000	No data	No data	100	0	0	545,000	0	375,000	0.083	0.032
Ecuador	2,500,000	2,500,000	0	No data	100	0	0	0			0.146	0.146
Egypt	2,425,000	0	500,000	0	0	100	0	1,925,000			0.025	0.005
El Salvador	250,000	No data	No data	No data				250,000	0	250,000	0.039	0.000
Eritrea	30,000	0	0	0	0	0	0	30,000	0	12,500	0.005	0.000
Estonia	499,800	499,800	No data	No data	100	0	0	0			0.378	0.378
Ethiopia	537,500	0	0	0	0	0	0	537,500	0	537,500	0.005	0.000
Finland	11,053,000	1,450,000	9,603,000	No data	13	87	0	0			2.003	2.003
Georgia	900,000	900,000	No data	No data	100	0	0				0.241	0.241
Germany	58,377,150	26,224,300	No data	No data	45	0	0	0			0.704	0.704
Ghana	50,000	No data	No data	No data				50,000	0	50,000	0.002	0.000
Greece	6,926,500	143,500	5,260,000	1,523,000	2	76	22	0			0.646	0.646
Guatemala	1,666,500	No data	No data	No data	0	0	0	0			0.097	0.097
Honduras	600,000	0	175,000	0	0	100	0	425,000	0	425,000	0.063	0.018
Hungary	6,000,000	6,000,000	0	0	100	0	0				0.614	0.614
India	85,150,000	80,000,000	0	0	100	0	0	5,150,000	0	5,150,000	0.063	0.059
Indonesia	504,500	No data	No data	No data				504,500	42,000	462,500	0.002	0.000
Iran	14,383,000	14,383,000	No data	No data	100	0	0	0			0.176	0.176
Iraq	12,000,000	0	12,000,000	0	0	100	0	0			0.312	0.312
Ireland	11,274,400	573,000	394,400	10,307,000	5	3	91	0			2.323	2.323
Jamaica	12,500	No data	No data	No data				12,500	0	12,500	0.004	0.000
Japan	113,718,000	No data	No data	No data	0	0	0	0			0.899	0.899
Jordan	2,624,460	1,700,000	0	0	100	0	0	924,460	74,460	850,000	0.264	0.171
Kenya	487,500	0	0	0	0	0	0	487,500	0	487,500	0.009	0.000
Korea, Republic of	62,498,000	3,335,000	59,163,000	No data	5	95	0				1.210	1.210
Kyrgyzstan	337,500	50,000	62,500	0	44	56	0	225,000	0	225,000	0.053	0.018
Latvia	943,500	943,500	0	0	100	0	0	0			0.490	0.490
Lebanon	56,500	No data	No data	No data				56,500	0	0	0.008	0.000
Lithuania	4,588,800	4,588,800	0	No data	100	0	0				1.645	1.645
Macedonia	1,219,000	1,219,000	0	0	100	0	0	0			0.585	0.585

	Factor IX total IU	Factor IX plasma derived	Factor IX recombinant	Factor IX recombinant, extended half life	Total percent plasma derived	Total percent recombinant	Total percent extended half life	Factor IX humanitarian aid total	Factor IX WFH humanitarian aid - conventional	Factor IX WFH humanitarian aid - extended half-life	Factor IX per capita	Factor IX per capital without humanitarian aid
Madagascar	412,500	0	0	0	0	0	0	412,500	0	412,500	0.016	0.000
Malawi	87,000	0	0	0	0	0	0	87,000	0	62,500	0.005	0.000
Malaysia	8,752,000	8,752,000	0	0	100	0	0	0			0.278	0.278
Maldives	35,000	No data	No data	No data				35,000	0	0	0.068	0.000
Mali	50,000	0	0	0	0	0	0	50,000	0	50,000	0.003	0
Mauritania	119,000	119,000	0	0	100	0	0	0	0	0	0.027	0.027
Mauritius	465,000	465,000	0	0	100	0	0	0			0.368	0.368
Mongolia	712,250	No data	541,000	71,250	0	88	12	100,000	0	100,000	0.225	0.193
Montenegro	250,000	250,000	0	0	100	0	0	0			0.402	0.402
Morocco	1,385,180	No data	250,000	No data	0	59	0	962,080	37,080	925,000	0.038	0.012
Mozambique	18,000	No data	No data	No data	0	0	0				0.001	0.001
Myanmar	697,000	No data	No data	No data				697,000	0	150,000	0.013	0.000
Nepal	525,000	No data	No data	No data				525,000	0	525,000	0.019	0.000
Nicaragua	100,000	0	0	0	0	0	0	100,000	0	100,000	0.015	0.000
Nigeria	160,984	0	0	0	0	0	0	160,984	35,984	125,000	0.001	0.000
Norway	3,581,500	1,105,000	400,000	2,076,500	31	11	58	0			0.674	0.674
Pakistan	1,767,500	522,500	0	0	100	0	0	1,245,000	0	0	0.008	0.002
Palestine	2,097,000	No data	No data	No data	0	0	0		0	0	0.459	0.459
Panama	181,200	181,200	0	No data	100	0	0	0			0.043	0.043
Paraguay	346,000	No data	No data	No data				346,000	0	175,000	0.050	0.000
Philippines	583,250	0	0	0	0	0	0	583,250	70,750	512,500	0.005	0.000
Poland	38,266,650	35,662,400	2,604,250	0	93	7	0	0			1.008	1.008
Portugal	7,913,000	4,100,000	3,813,000	No data	52	48	0				0.770	0.770
Qatar	3,000,000	0	No data	No data	0	0	0	0			1.078	1.078
Romania	6,900,000	No data	No data	No data	0	0	0				0.354	0.354
Russia	151,026,825	151,026,825	0	0	100	0	0	0			1.045	1.045
Saudi Arabia	12,000,000	7,000,000	4,000,000	1,000,000	58	33	8	0			0.356	0.356
Senegal	100,000	0	0	0	0	0	0	100,000	0	100,000	0.006	0.000
Serbia	3,065,900	980,900	2,085,000	0	32	68	0				0.439	0.439
Singapore	2,205,500	549,000	1,656,500	0	25	75	0	0			0.391	0.391
Slovak Republic	3,821,800	2,871,800	200,000	750,000	75	5	20	0			0.702	0.702
Slovenia	1,188,500	183,500	814,000	191,000	15	68	16	0			0.575	0.575
South Africa	9,657,500	9,657,500	0	No data	100	0	0	0			0.167	0.167

	Factor IX total IU	Factor IX plasma derived	Factor IX recombinant	Factor IX recombinant, extended half life	Total percent plasma derived	Total percent recombinant	Total percent extended half life	Factor IX humanitarian aid total	Factor IX WFH humanitarian aid - conventional	Factor IX WFH humanitarian aid - extended half-life	Factor IX per capita	Factor IX per capital without humanitarian aid
Sri Lanka	300,000	No data	No data	No data				300,000	0	300,000	0.014	0.000
Sudan	1,300,000	1,300,000	0	0	100	0	0	0			0.031	0.031
Sweden	22,751,200	9,652,200	12,459,000	640,000	42	55	3	0			2.234	2.234
Syria	1,362,500	1,360,000	0	0	100	0	0	2,500			0.081	0.080
Tanzania	50,000	No data	No data	No data				50,000	0	50,000	0.001	0.000
Thailand	2,826,000	2,826,000	No data	No data	100	0	0		0	0	0.041	0.041
Tunisia	2,065,500	2,065,500	0	0	100	0	0	0			0.179	0.179
Uganda	276,036	No data	No data	No data				276,036	0	275,000	0.006	0.000
Ukraine	20,929,200	2,203,600	8,261,000	0	21	79	0	10,464,600			0.469	0.235
United Kingdom	78,798,086	5,187,410	50,079,000	23,531,676	7	64	30	0			1.185	1.185
United States	540,000,000	55,000,000	265,000,000	220,000,000	10	49	41				1.651	1.651
Uruguay	600,000	No data	0	0	0	0	0	0			0.174	0.174
Uzbekistan	1,150,000	300,000	425,000	No data	41	59	0	425,000	0	425,000	0.035	0.022
Venezuela	2,475,000	0	0	0	0	0	0	2,475,000	0	1,325,000	0.086	0.000
Vietnam	4,062,000	3,958,350	No data	No data	100	0	0	103,650			0.043	0.041
Zambia	300,000	No data	No data	No data				300,000	50,000	250,000	0.017	0.000
TOTAL	**1,678,185,231**	**672,461,838**	**533,431,722**	**278,334,161**				**33,487,060**	**404,774**	**16,162,500**		

TABLE 19. **Use of Hemlibra in 2018**

Country	Number of patients with inhibitors treated with Hemlibra	Number of patients without inhibitors treated with Hemlibra	Total Hemlibra purchased (mg)
Chile	1	0	0
Colombia	5	0	0
Czech Republic	2	0	810
Estonia	1	N/A	0
Hungary	4	N/A	0
Ireland	4	4	6,450
Israel	20	30	0
Lithuania	1	N/A	0
Malaysia	6	0	0
Morocco	3	0	0
Netherlands	11	N/A	0
New Zealand	2	0	0
Norway	4	N/A	0
Poland	7	10	0
Portugal	16	N/A	10,770
Qatar	0	0	0
Saudi Arabia	5	0	0
Singapore	2	0	960
Slovak Republic	1	N/A	0
Slovenia	1	N/A	1,375
Sweden	7	0	5,400
Thailand	3	3	0
United Kingdom	36	N/A	91,055
United States	N/A	N/A	1,700,000

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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):
Have all the identified patients in your country been included in this report? If not, please explain.	Yes ☐ No ☐ Please explain:

Please Click Here **to validate Data source**

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B. Identified Patients

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

(Please DO NOT estimate or guess)	Total	Male	Female	Gender unknown	No data
1a. Total number of identified people with **hemophilia A**					☐
1b. Total number of identified people with **hemophilia B**					☐
1c. Total number of identified people with **hemophilia type unknown**					☐

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.					
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 thrombasthenia					☐
Platelet disorders: Bernard Soulier Syndrome					☐
Platelet disorders: other or unknown					☐

The sum of Total of the all other bleeding and platelets disorders should be equal to the number of OBD in question 3

A woman who has ≤40% 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 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	☐	☐	☐	☐

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The age distribution of Hemophilia A, B and unknown should be equal to the number of PWH in 1.
The age distribution of vWD should be equal to the number of vWD in question 2.

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. 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 ☐

7. 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 ≤40% 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 1.
The sum of Hemophilia A Female mild, moderate, severe and unknown should be equal to number of Hemophilia A female in question 1.
The sum of Hemophilia B Male mild, moderate, severe and unknown should be equal to number of Hemophilia B Male in question 1.
The sum of Hemophilia B Female mild, moderate, severe and unknown should be equal to number of Hemophilia B female in question 1.

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

8. 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 ☐

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9. INHIBITORS: Number of identified people with hemophilia with current clinically significant inhibitors in 2018. (Patients who do not respond to normal treatment.)

Type of hemophilia	Total number with active inhibitors	New cases of inhibitors in 2018	No Data
Hemophilia A			☐
Hemophilia B			☐

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

10 A. Availability and usage of products to treat hemophilia

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

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

10 B. Availability and usage of non-factor products to treat hemophilia with inhibitors

Treatment product	Product is available	Number of patients treated with product indicated	No data
Hemlibra (Emicizumab)	☐		☐

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

10 C. Availability and usage of non-factor products to treat hemophilia without inhibitors

Treatment product	Product is available	Number of patients treated with product indicated	No data
Hemlibra (Emicizumab)	☐		☐

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

11. Availability and usage of products to treat VWD

Treatment product	Product is available	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.

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12. 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 2018			

13. 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 2018			

[1]Hepatitis C antibody positive at any time

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

14. Number and cause of deaths of people with bleeding disorders (January 1-December 31, 2018)

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.

15. 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.

16. What percentage of children (18 and under) **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 # of patients with inhibitors who received ITI in your country in the last year, and the number of new patients who started ITI during the last year. Please indicate if these #s are precise or an estimate.

17. What is the total number of patients **with inhibitors** who received ITI during the last year?		Precise: ☐ Estimate: ☐	Not known ☐
Of this total, how many were new patients who **started** ITI treatment during the last year?		Precise: ☐ Estimate: ☐	Not known ☐

Please Click Here **to validate Care section**

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D. The Cost and Use of Factor Concentrates

18 A. Annual usage of purchased factor concentrates (please do not include donated factor)	**Factor VIII**	**Not known**	**Factor IX**	**Not known**
IN TOTAL how many international units (IU) of factor concentrates were used in your country in 2018 (excluding donated factor)?		☐		☐
Plasma derived: How many international units of **plasma-derived** concentrates were used in your country in 2018 (excluding donated factor)?		☐		☐
Recombinant, excluding extended half-life: How many international units of **recombinant** concentrates **(excluding extended half-life)** were used in your country in 2018 (excluding donated factor)?		☐		☐
Recombinant, extended half-life: How many international units of **recombinant** concentrates**, extended half-life** were used in your country in 2018 (excluding donated factor)?		☐		☐
If factor concentrates are purchased in your country but you are unable to report the quantities please check here:	☐		☐	

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

18 B. Annual usage of donated factor concentrates	**Factor VIII**	**Not known**	**Factor IX**	**Not known**
How many international units of **donated factor** concentrates (plasma-derived or recombinant) from all sources, including **Humanitarian Aid,** were used in your country in 2018?		☐		☐

18 C. Annual usage of purchased Hemlibra (Emicizumab)	**Amount (mg)**	**Not known**
How many milligrams (mg) of Hemlibra were purchased in your country in 2018? (Excluding donated product)		☐

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**

19. Factor VIII Concentrates used in 2018

(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 (now part of Shire)	
☐	Adynovate	Baxalta (now part of Shire)	
☐	Aleviate	CSL Behring	
☐	Alphanate	Grifols	
☐	Amofil	Sanquin OY	
☐	Bioclot A	Biofarma	
☐	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	
☐	HEMO-8R	HEMOBRAS	
☐	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 (now part of Shire)	
☐	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	
☐	Octofactor	Generium/Pharmstandart	
☐	Optivate	Bio Products Laboratory	
☐	FVIII by Quimbiotec	Quimbiotec	
☐	Recombinate rAHF	Baxalta (now part of Shire)	
☐	ReFacto AF	Pfizer (Wyeth)	
☐	Replenate	Bio Products Laboratory	
☐	TBSF purity factor, Koate DVI	Grifols	
☐	UNC Hemoderivados	Laboratorio de Hemoderivados de Universidad Nacional de Córdoba	
☐	Vihuma	Biotest	
☐	Voncento	CSL Behring	
☐	Western Province factor8 VIAHF	Western Province Blood transfusion Service	
☐	Wilate	Octapharma	
☐	Xyntha	Pfizer (Wyeth)	
☐	Other:		

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

20. Factor IX Concentrates used in 2018

(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	
☐	Clotnine	Hemarus	
☐	Factor IX Grifols	Grifols	
☐	Faktor IX SDN	Biotest	
☐	Fixnove	Baxalta (now part of Shire)	
☐	Hemo-B-RAAS	Shanghai RAAS	
☐	Haemonine	Biotest	
☐	Humafactor IX	Kedrion	

☐	Immunine	Baxalta (now part of Shire)	
☐	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.	
☐	Rixubis	Baxalta (now part of Shire)	
☐	Other:		

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

21. Prothrombin Complex Concentrates used in 2018

(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 (now part of Shire)	
☐	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 (now part of Shire)	
☐	Prothrombinex PXT	CSL Bioplasma	
☐	Prothrombinex- VF	CSL Bioplasma	
☐	Prothromplex-T	Baxalta (now part of Shire)	
☐	Prothroraas	Shanghai RAAS	
☐	UMAN Complex D.I.	Kedrion	
☐	Other:		

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

22. Other Products used in 2018

(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	
☐	Byclot (1.5mg)	Kaketusken	
☐	Ceprotin	Baxalta (now part of Shire)	
☐	Clottafact Wilstart	LFB	
☐	Clottagen (fibrinogen)	LFB	
☐	Coagil 7 (activated factor VII)	Pharmstandard	Price per vial: Vial size:
☐	FACTEUR VII	LFB	
☐	Factor VII	Baxalta (now part of Shire)	
☐	Factor VII	Bio Products	
☐	Factor X P Behring	CSL Behring	
☐	Factor XI	Bio Products	
☐	FEIBA	Baxalta (now part of Shire)	
☐	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	
☐	Kovaltry	Bayer	
☐	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.

23. Non-factor products used in 2018

(Please check the box on the left if a product is used, and if known, fill out the number of patients and price per dose.)

Used	Brand Name	Manufacturer	Price per Dose
☐	Hemlibra (Emicizumab)	Roche	

Please return to:

Email: globalsurvey@wfh.org

Fax: 514-875-8916

Address: **World Federation of Hemophilia**
1425 René Lévesque Boulevard West, suite 1200
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.

Extended half-life factor concentrate: A new generation of recombinant factor concentrates, which extend their half-life. Half-life is the time is takes for infused factor to lose half of its potency. Traditional factor VIII has a half-life of 8 to 12 hours; an extended factor VIII half-life is defined as a ratio greater than 1.3-fold, of the traditional high-life.

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 above 5% and below 40% of normal activity in the bloodstream. (National definitions differ on the upper limit for mild hemophilia, ranging from 24% to 50%.)

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.

Notes

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WORLD FEDERATION OF HEMOPHILIA
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