WORLD FEDERATION OF HEMOPHILIA

REPORT ON THE

ANNUAL GLOBAL SURVEY 2020

WFH

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

October 2021

Report on the Annual Global Survey 2020 is published by the World Federation of Hemophilia.

All data are provisional.

World Federation of Hemophilia
1425, boul. René-Lévesque Ouest, bureau 1200
Montréal, Québec H3G 1T7
Canada
Tel. (514) 875-7944
Fax: (514) 875-8916
E-mail: wfh@wfh.org
Website: www.wfh.org

TABLE OF CONTENTS

INTRODUCTION TO THE REPORT ON THE ANNUAL GLOBAL SURVEY 2020

The Report on the Annual Global Survey (AGS) 2020 shows an international snapshot of hemophilia patient identification and access to care. This report includes selected demographic and treatment data on people with hemophilia (PWH), von Willebrand disease (VWD), other rare factor deficiencies, and inherited platelet disorders throughout the world. 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 strives for continuous improvement every year and is appreciative of all the effort and support put forth by the NMOs.

Supplementary charts and graphs using 2020 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 questionnaire is 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 2020

This report has been divided into two parts: Part one shows the total number of identified people with bleeding disorders (PWBD) reported globally since 1999. It includes the last reported number of PWBD by a country, regardless of the year reported, under the assumption that the number of people with bleeding disorders did not change substantially from one year to the next. Part two shows only the data that was reported by a country in this specific year. A list of participating countries and the last year they provided data can be found on page 10.

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 number from The World Bank Group are used in population statistics and in the calculation for factor VIII and IX per capita. The regional classification used in the AGS is based on the WHO regional classification.[1]

Comments on data collection

Participation in the AGS is voluntary and some countries are only able to provide detailed data on sex, age, inhibitors and HIV/HCV infection for a limited subset of patients. In some cases the numbers reported may be based on an estimate or from one region or certain treatment centres only.

Not all NMOs are able to report on all treatment products purchased and used in their country. The amounts reported may only be treatment bought through government and not through other sources. Quantities reported are not independently verified except when the WFH has data on humanitarian donations it provided in 2020. 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.

Calculating prevalence and prevalence at birth of hemophilia

In 2003, the World Federation of Hemophilia estimated that 400,000 patients with hemophilia were expected globally. This figure came from then-current estimate of the prevalence of hemophilia (e.g., 13.4 per 100,000 males and global population of 6 billion), based on US CDC data,[2] and did not distinguish severe from mild patients.

Over the subsequent years, three main findings became available:

a) The large variability of hemophilia incidence and prevalence across countries was measured and the impact of socio-economic status was highlighted[3,4]
b) Many large studies focusing on inhibitor development provided new data on previously untreated patients (PUPs) and prevalence at birth of hemophilia[5]
c) The importance of distinguishing a) the number of mild and severe hemophilia patients and b) the difference between prevalence at birth and prevalence over the whole population as indexes of maturity of the health care system.[6]

New data on prevalence at birth (incidence) and prevalence has been recently estimated, separately for severe and all patients.[7] The prevalence at birth was estimated from the FranceCoag data, and confirmed with data from the United Kingdom and Canadian registries. Specifically, the number of patients by year of birth was retrospectively assessed and analyzed over many years. This novel approach estimates the prevalence at birth of hemophilia patients:

24.6/100,000 males for ALL hemophilia A	9.5/100,000 males for severe hemophilia A
5.0/100,000 males for ALL hemophilia B	1.5/100,000 males for severe hemophilia B

Using these new estimates for prevalence at birth and the current live birth population globally from UNICEF (at least 130 million babies are born each year) approximately 20,000 people with hemophilia to be born worldwide each year, of which about 7,000 are severe.

Unfortunately, the mortality rate for people with hemophilia is higher than the mortality rate in the general population due to inadequate care over a patient's lifetime (e.g., limited to no treatment, HIV/AIDS, HBV, and HCV). As a result, we estimated the prevalence of hemophilia using registry data from Australia, Canada, France, Italy, New Zealand, and the United Kingdom:

17.1/100,000 males for ALL hemophilia A	6.0/100,000 males for severe hemophilia A
3.8/100,000 males for ALL hemophilia B	1.1/100,000 males for severe hemophilia B

Using these estimates and the current world male population of 7.8 billion (3.9 billion males), the expected number of patients with hemophilia worldwide is 815,100, of which about 276,900 are severe.

In this report, the prevalence rate is used to calculate the expected number of patients per region (Figure C). This number is sequentially compared to the identified number of patients reported in this survey to illustrate the progress in patient outreach, identification, and diagnostic capabilities globally and to identify areas for improvement.

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 287,371 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:

Chair:	Jeff Stonebraker	**Annual Global Survey Reviewers:**
Members:	Magdy El Ekiaby	Paula Bolton-Maggs (Past Chair)
	Emna Gouider	Randall Curtis
	Alfonso Iorio (Past Chair)	Suely Rezende
	Mike Makris	Mike Soucie
	Jamie O'Hara	Alok Srivastava
	Glenn Pierce	
	Michael Recht	

Part 1: Global Data 1999–2020

GLOBAL REPRESENTATION OVER TIME (1999–2020)

Since 1999, there have been 144 different countries that have reported data to the Annual Global Survey. This infographic 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. This section was added to illustrate a more complete representation of the current state of patient identification globally.

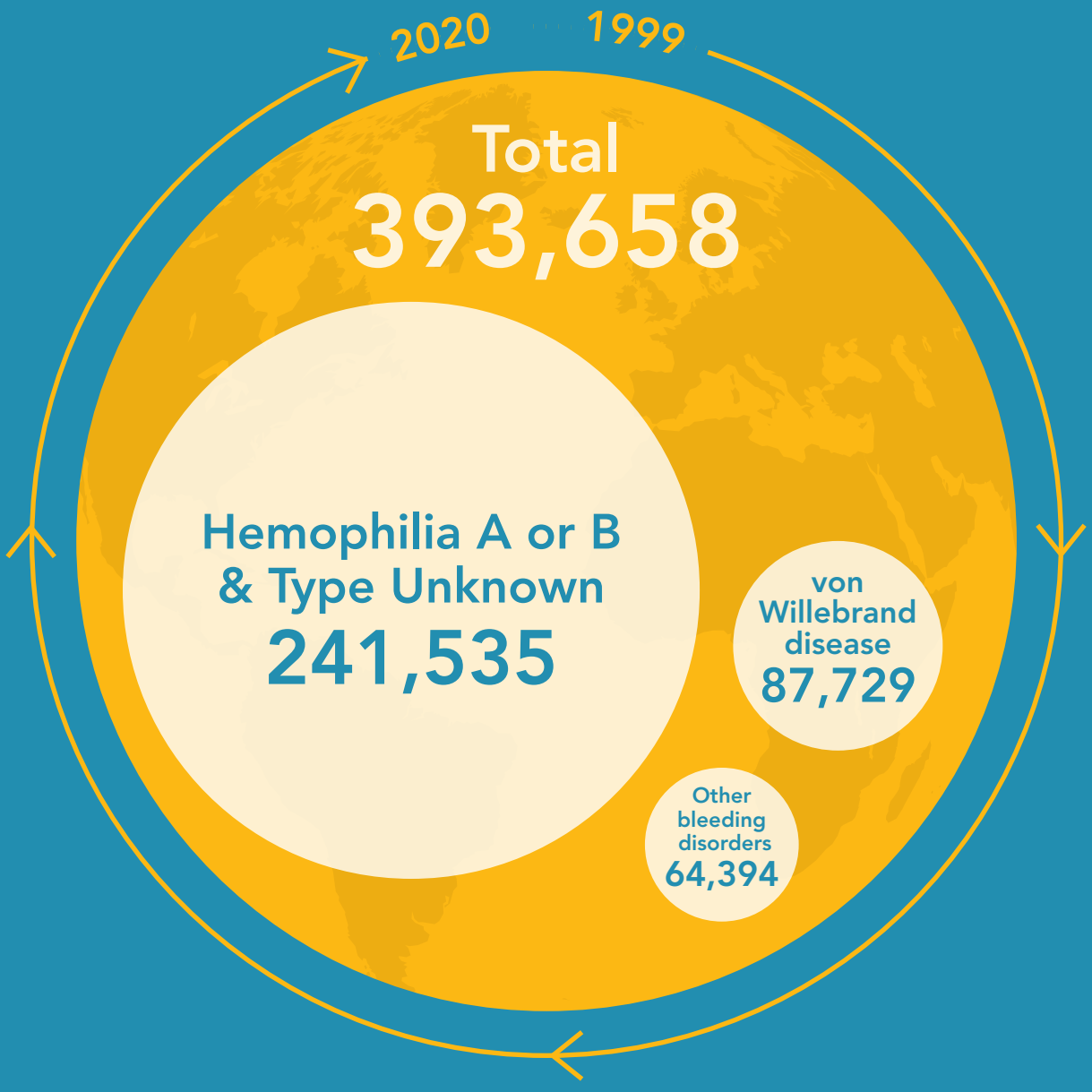


FIGURE A1. **Identified patients over time – all bleeding disorders**

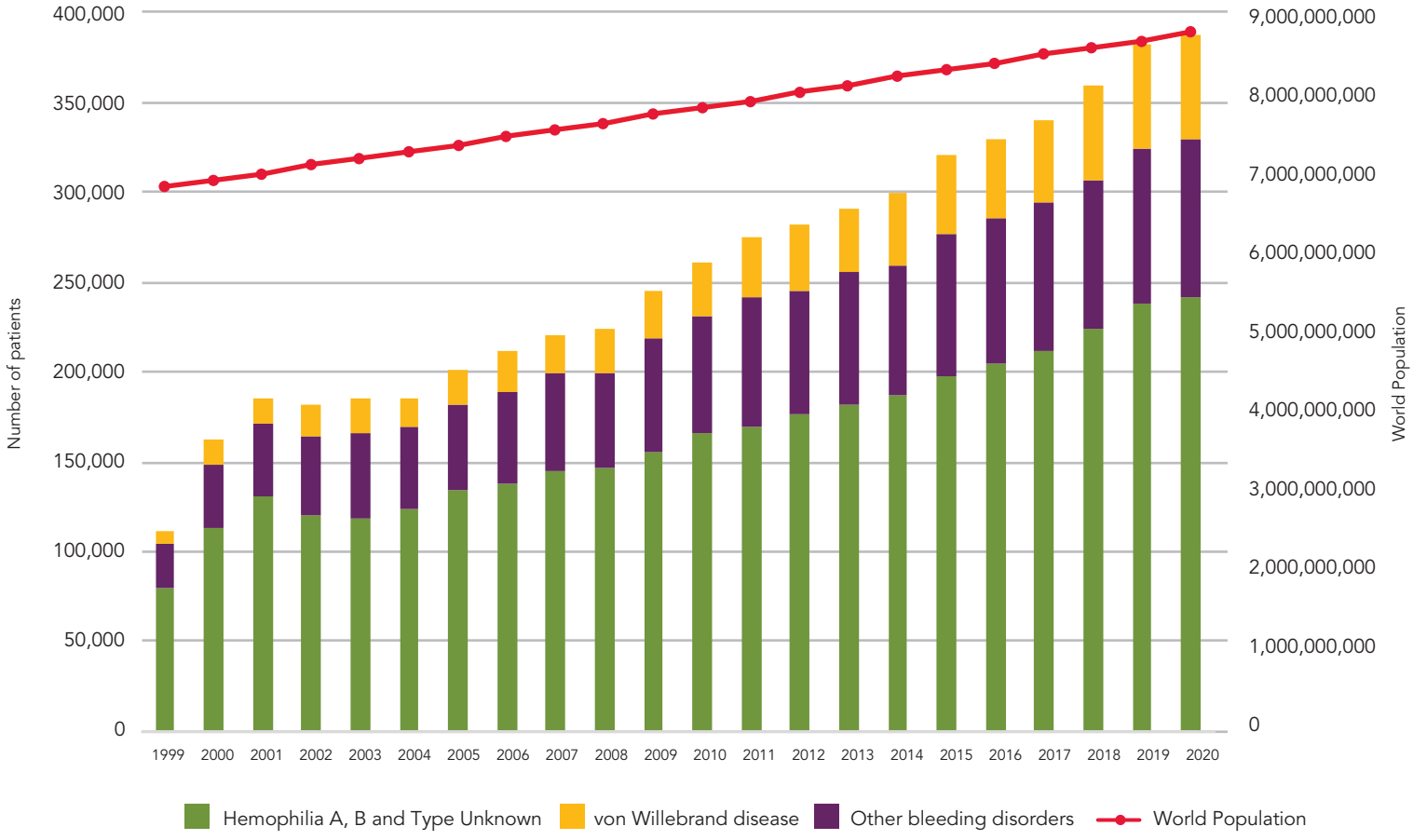


FIGURE A2. **Identified patients over time – other rare bleeding disorders**

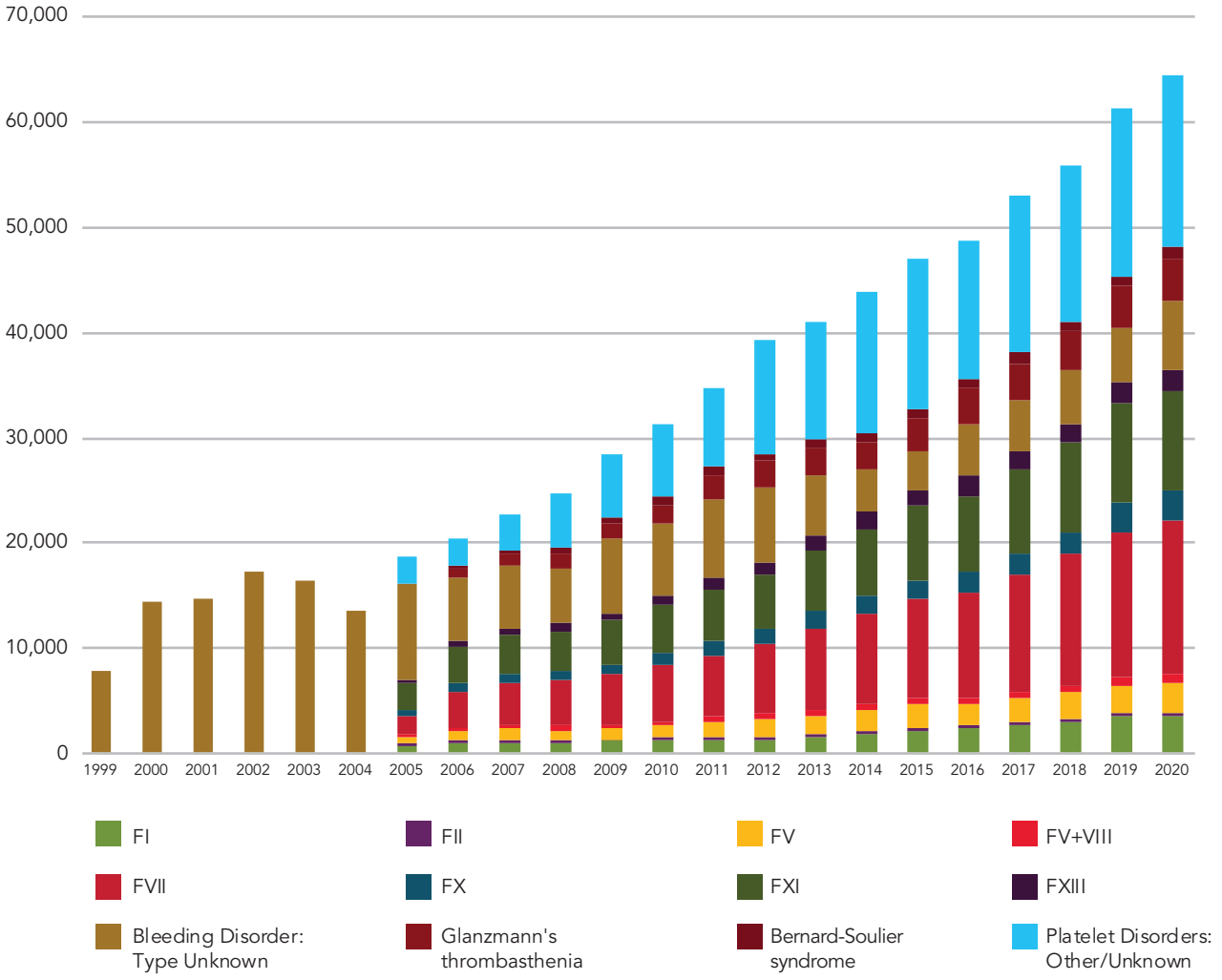


TABLE 1. **National member organizations and their latest year of reporting.**

Please note: Not all of our members are able to submit data every year. The year indicates the latest year the data was submitted. For the 2020 survey report, 120 countries submitted data and can be found in **BOLD** in the table below.

Country	Last year of submission	Total number of submissions
Afghanistan	**2020**	**5**
Albania	**2020**	**17**
Algeria	**2020**	**17**
Angola	**2020**	**1**
Argentina	**2020**	**21**
Armenia	**2020**	**11**
Australia	**2020**	**22**
Austria	**2020**	**16**
Azerbaijan	2018	14
Bahamas	**2020**	**3**
Bahrain	2014	5
Bangladesh	**2020**	**22**
Barbados	**2020**	**4**
Belarus	**2020**	**14**
Belgium	**2020**	**20**
Belize	**2020**	**14**
Benin	2018	1
Bolivia	**2020**	**9**
Bosnia-Herzegovina	2019	6
Botswana	**2020**	**4**
Brazil	**2020**	**21**
Bulgaria	2018	10
Burkina Faso	**2020**	**5**
Cambodia	**2020**	**14**
Cameroon	**2020**	**14**
Canada	**2020**	**21**
Chile	**2020**	**13**
China	2018	12
Colombia	**2020**	**21**
Costa Rica	**2020**	**21**
Cote d'Ivoire	**2020**	**13**
Croatia	2007	6
Cuba	**2020**	**18**
Cyprus	2013	7

Country	Last year of submission	Total number of submissions
Czech Republic	**2020**	**15**
Denmark	2018	14
Djibouti	**2020**	**1**
Dominican Republic	**2020**	**19**
Ecuador	**2020**	**15**
Egypt	**2020**	**19**
El Salvador	**2020**	**8**
Eritrea	**2020**	**13**
Estonia	**2020**	**12**
Ethiopia	**2020**	**10**
Finland	**2020**	**16**
France	**2020**	**18**
Georgia	**2020**	**19**
Germany	**2020**	**22**
Ghana	**2020**	**10**
Greece	**2020**	**21**
Guatemala	2019	10
Guyana	**2020**	**4**
Honduras	**2020**	**19**
Hong Kong (China)	2018	3
Hungary	**2020**	**19**
Iceland	2007	6
India	**2020**	**20**
Indonesia	**2020**	**17**
Iran	**2020**	**21**
Iraq	**2020**	**17**
Ireland	**2020**	**22**
Israel	**2020**	**15**
Italy	**2020**	**13**
Jamaica	**2020**	**11**
Japan	**2020**	**21**
Jordan	**2020**	**15**
Kazakhstan	2008	1
Kenya	**2020**	**19**

Country	Last year of submission	Total number of submissions
Korea, Republic of	**2020**	**22**
Kuwait	2019	1
Kyrgyzstan	2018	7
Latvia	**2020**	**22**
Lebanon	**2020**	**11**
Lesotho	**2020**	**14**
Lithuania	**2020**	**21**
Luxembourg	2001	3
Macedonia	2018	9
Madagascar	**2020**	**5**
Malawi	**2020**	**5**
Malaysia	**2020**	**20**
Maldives	**2020**	**7**
Mali	**2020**	**5**
Malta	**2020**	**5**
Mauritania	**2020**	**4**
Mauritius	**2020**	**10**
Mexico	**2020**	**19**
Moldova	2017	11
Mongolia	**2020**	**14**
Montenegro	**2020**	**6**
Morocco	**2020**	**8**
Mozambique	**2020**	**4**
Myanmar	2019	3
Namibia	**2020**	**2**
Nepal	**2020**	**21**
Netherlands	**2020**	**16**
New Zealand	**2020**	**22**
Nicaragua	**2020**	**16**
Nigeria	**2020**	**13**
Norway	**2020**	**16**
Oman	2016	6
Pakistan	**2020**	**20**
Palestine	**2020**	**10**
Panama	**2020**	**19**
Paraguay	**2020**	**8**
Peru	**2020**	**11**
Philippines	**2020**	**18**
Poland	**2020**	**22**

Country	Last year of submission	Total number of submissions
Portugal	**2020**	**22**
Qatar	**2020**	**10**
Romania	**2020**	**17**
Russia	**2020**	**21**
Saudi Arabia	**2020**	**13**
Senegal	**2020**	**16**
Serbia	**2020**	**14**
Sierra Leone	1999	1
Singapore	**2020**	**12**
Slovak Republic	**2020**	**19**
Slovenia	**2020**	**15**
South Africa	**2020**	**21**
Spain	**2020**	**14**
Sri Lanka	**2020**	**12**
Sudan	**2020**	**17**
Suriname	**2020**	**4**
Sweden	**2020**	**16**
Switzerland	**2020**	**17**
Syria	**2020**	**10**
Tajikistan	**2020**	**3**
Tanzania	**2020**	**9**
Thailand	**2020**	**20**
Togo	**2020**	**9**
Trinidad and Tobago	2019	1
Tunisia	**2020**	**16**
Turkey	2014	16
Uganda	**2020**	**10**
Ukraine	**2020**	**13**
United Arab Emirates	2015	1
United Kingdom	**2020**	**21**
United States	**2020**	**21**
Uruguay	**2020**	**13**
Uzbekistan	**2020**	**18**
Venezuela	**2020**	**22**
Vietnam	**2020**	**18**
Zambia	**2020**	**6**
Zimbabwe	**2020**	**16**

Part 2:
2020 Data

KEY NUMBERS FROM THE REPORT ON THE ANNUAL GLOBAL SURVEY 2020

For all tables and graphs from this point onwards, the analyses were done using only data from countries that responded in 2020.

120 **NUMBER OF COUNTRIES**
in this survey

RESPONSE RATE
from WFH National Member Organizations

82%
(120/147)

347,026
NUMBER OF IDENTIFIED PATIENTS

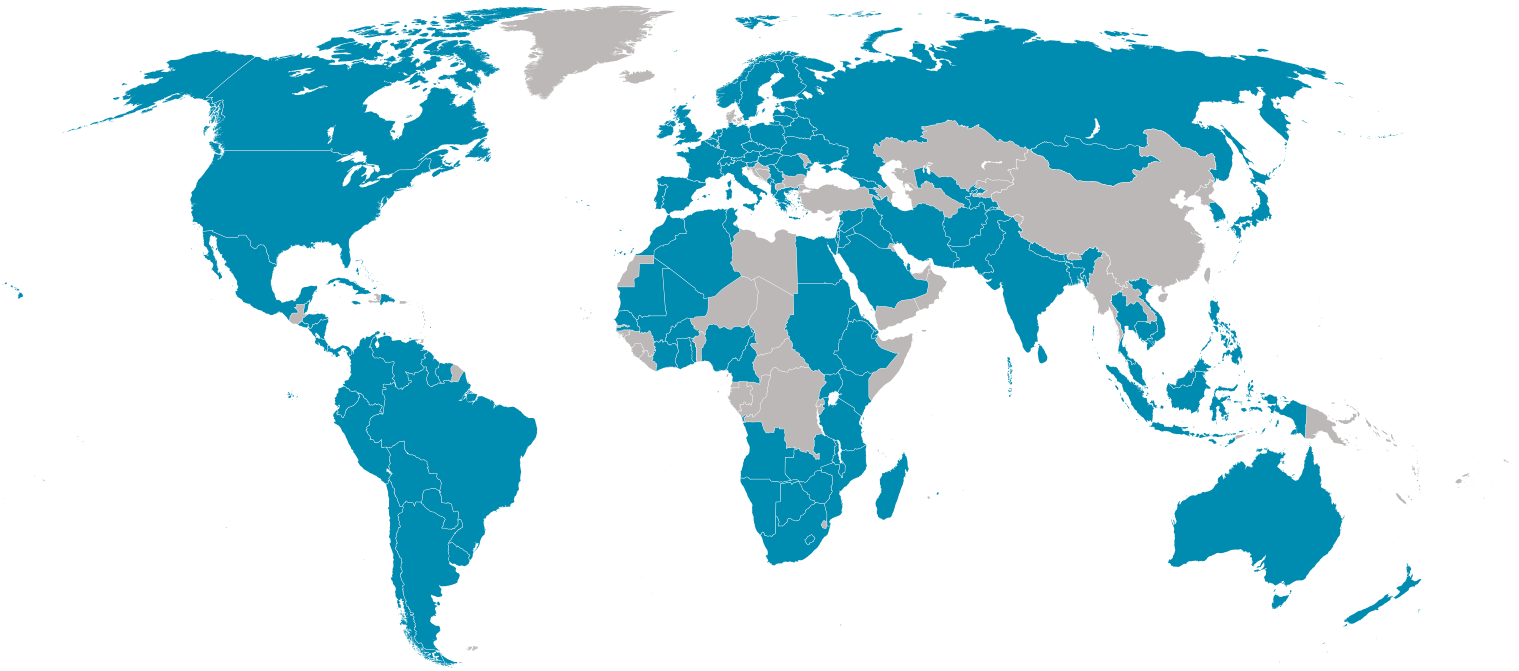
209,614	People with hemophilia
165,379	Hemophilia A
33,076	Hemophilia B
11,159	Hemophilia type unknown
84,197	von Willebrand disease
53,215	Other bleeding disorders

FACTOR VIII USAGE PER CAPITA
0.945 IU (0.106-4.469) Median (IQR)
105 countries

FACTOR IX USAGE PER CAPITA
0.13 IU (0.015-0.662) Median (IQR)
98 countries

COUNTRY REPRESENTATION

Annual Global Survey 2020



2020 Data Respondents

The WFH has a total of 147 national member organizations (NMOs). The Report on the Annual Global Survey 2020 includes data from 120 NMOs.

FIGURE B1. **Country representation by region**

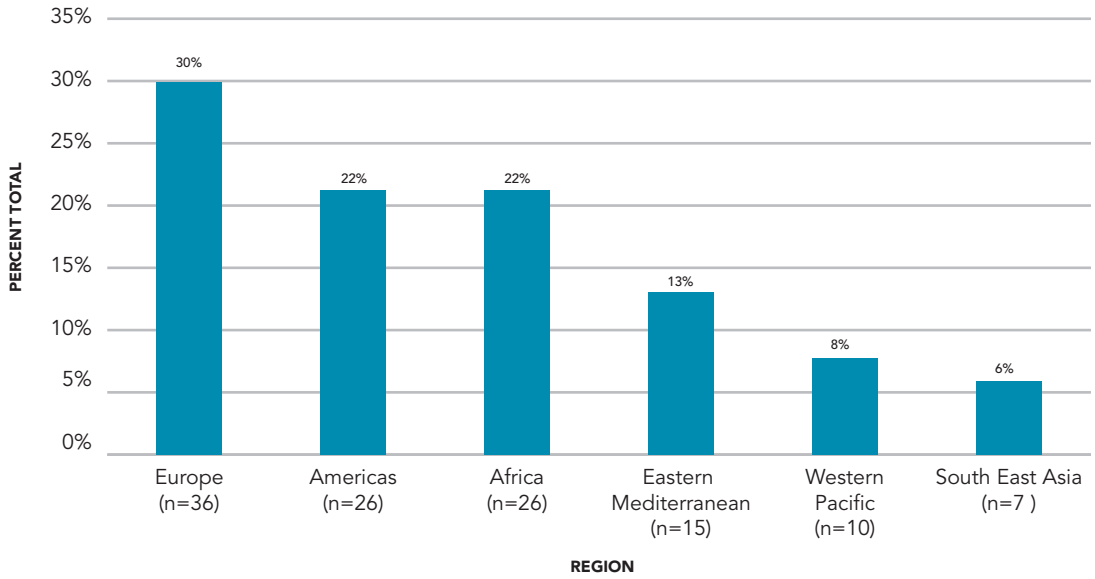
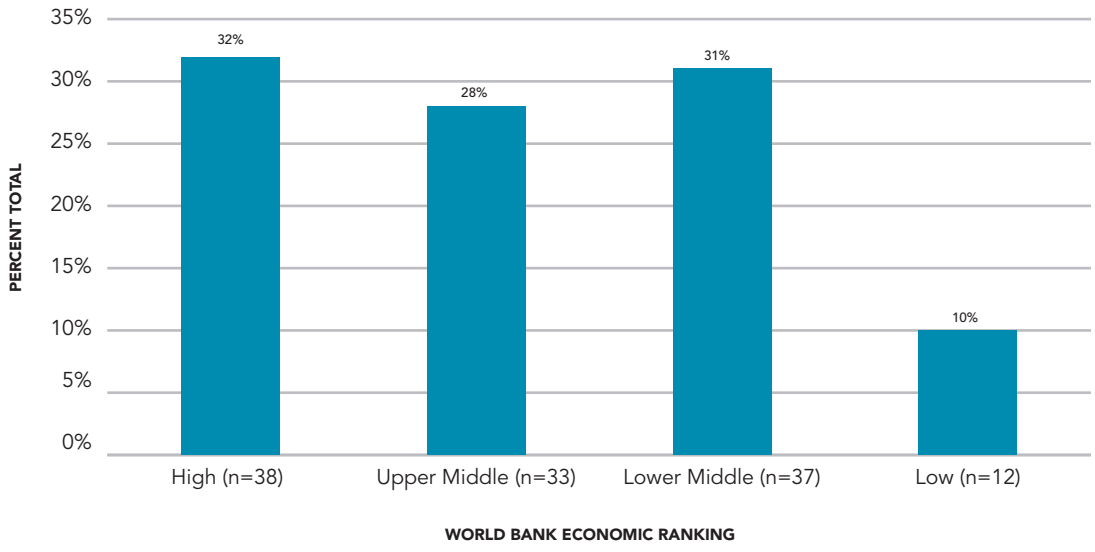


FIGURE B2. **Country representation by gross national income**



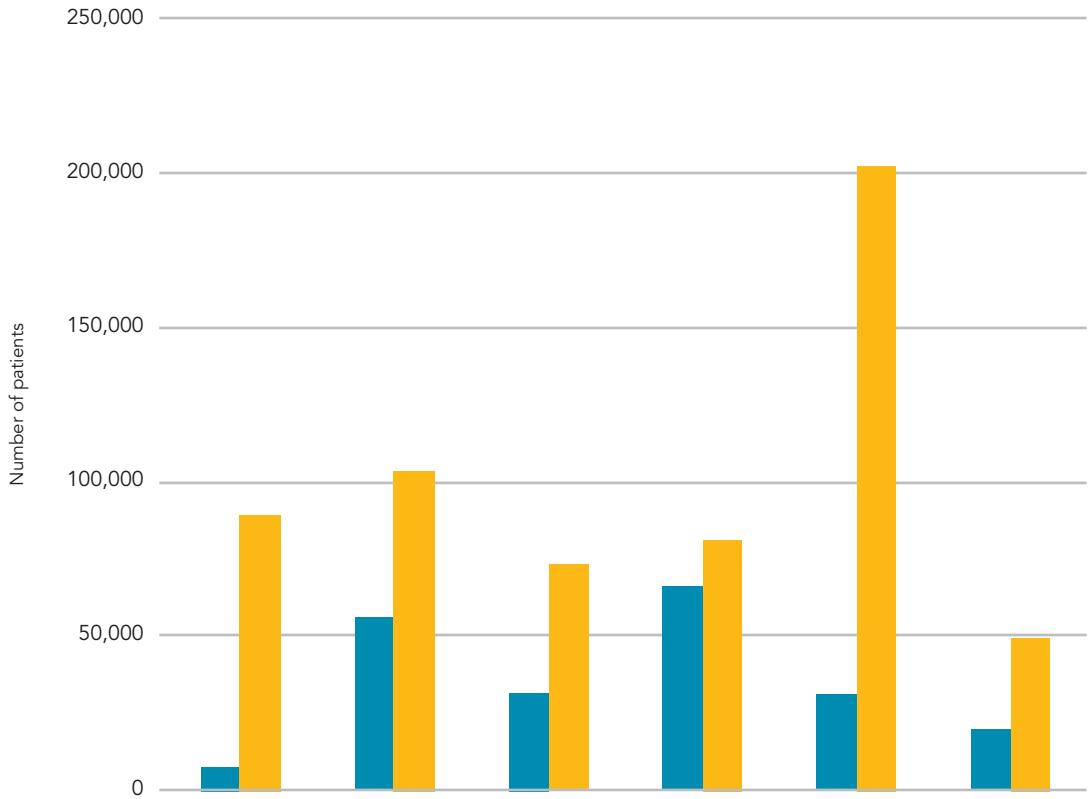
Economic category based on The World Bank Group 2020 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,045; C lower middle income, $1,046–$4,095; B upper middle income, $4,096–$12,695; and A high income, $12,695 or more.

REPORT ON THE ANNUAL GLOBAL SURVEY 2020 SUMMARY DEMOGRAPHICS

TABLE 2. **Demographics**

	2020 Total
Number of countries in this survey	**120**
World population covered by countries in this survey report	**5,728,473,350**
Total number of people with bleeding disorders	**347,026**
Number of people with Hemophilia	**209,614**
Number of people with hemophilia A	**165,379**
Number of people with hemophilia B	**33,076**
Number of people with hemophilia type unknown or type not reported	**11,159**
Number of people with VWD	**84,197**
Number of people with Other Bleeding Disorders	**53,215**

FIGURE C. **Number of identified vs. expected hemophilia patients by region**



	Africa	Americas	Eastern Mediterranean	Europe	South East Asia	Western Pacific
Identified number of patients	7,251	55,287	30,595	65,778	31,336	19,367
Expected number of patients	89,026	103,006	73,132	81,306	202,690	49,466
Percent of identified patients	**8%**	**54%**	**42%**	**81%**	**15%**	**39%**

This graph was created by calculating expected number of patients using the prevalence of 20.9 per 100,000 males in hemophilia.[7]

FACTOR USAGE SUMMARY

TABLE 3. **Factor VIII usage 2020**

	FACTOR USAGE	NUMBER OF COUNTRIES REPORTING
Mean (SD) global per capita factor VIII usage	**2.551 IU (3.108)**	**105**
Median global per capita factor VIII usage	**0.945**	**105**
Interquartile range (IQR) global per capita factor VIII usage	**4.363 IU (0.106 to 4.469)**	**105**
Total consumption of factor VIII concentrates	**11,116,204,164 IU**	**105**

TABLE 4. **Factor IX usage 2020**

	FACTOR USAGE	NUMBER OF COUNTRIES REPORTING
Mean (SD) global per capita factor IX usage	**0.485 IU (0.872)**	**98**
Median global per capita factor IX usage	**0.13 IU**	**98**
Interquartile range (IQR) global per capita factor IX usage	**0.647 IU (0.015 to 0.662)**	**98**
Total consumption of factor VIII concentrates	**2,202,597,368 IU**	**98**

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).

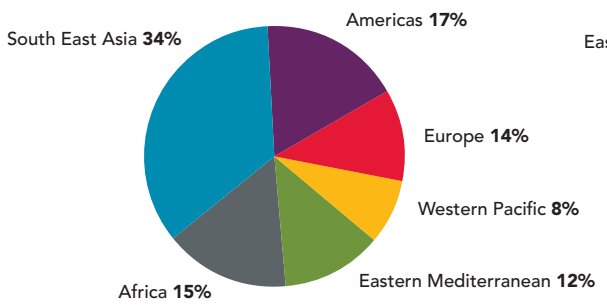
TABLE 5. **Factor use in 2019 and 2020**

	2019	2020	NUMBER OF COUNTRIES REPORTING
FACTOR VIII			
Mean (SD) global per capita factor VIII usage	2.591 IU (3.146)	2.543 IU (3.067)	95
Median global per capita factor VIII usage	1.058 IU	0.954 IU	95
Interquartile range (IQR) global per capita factor VIII usage	4.143 IU (0.168 to 4.311)	4.266 IU (0.121 to 4.387)	95
FACTOR IX			
Mean (SD) global per capita factor IX usage	0.436 IU (0.625)	0.445 IU (0.626)	86
Median global per capita factor IX usage	0.164 IU	0.177 IU	86
Interquartile range (IQR) global per capita factor IX usage	0.654 IU (0.018 to 0.672)	0.639 IU (0.017 to 0.656)	86

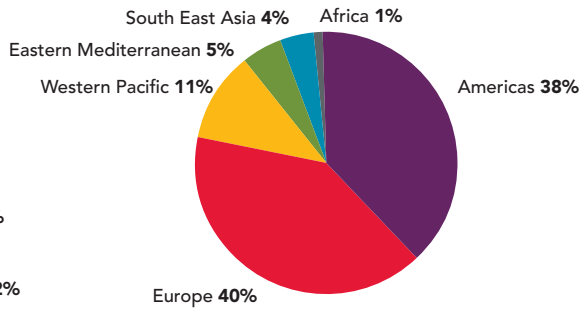
This table show the mean, median and interquartile range (IQR) of per capita factor usage for the countries that reported in both years indicated. The standard deviation (SD) describes the amount of variation of dispersion from the mean. The interquartile range (IQR) describes the middle 50% of reported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

FIGURE D. **Global distribution of factor VIII use**

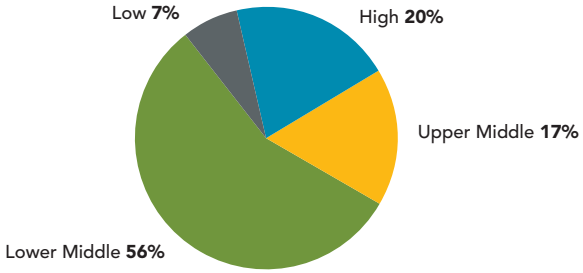
Population by region



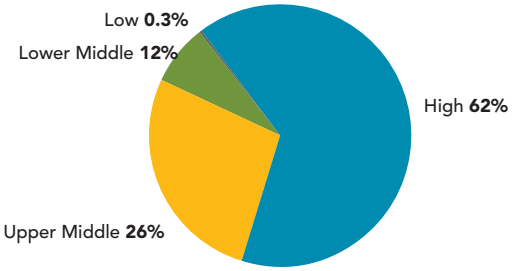
FVIII total IU by region



Population by gross national income



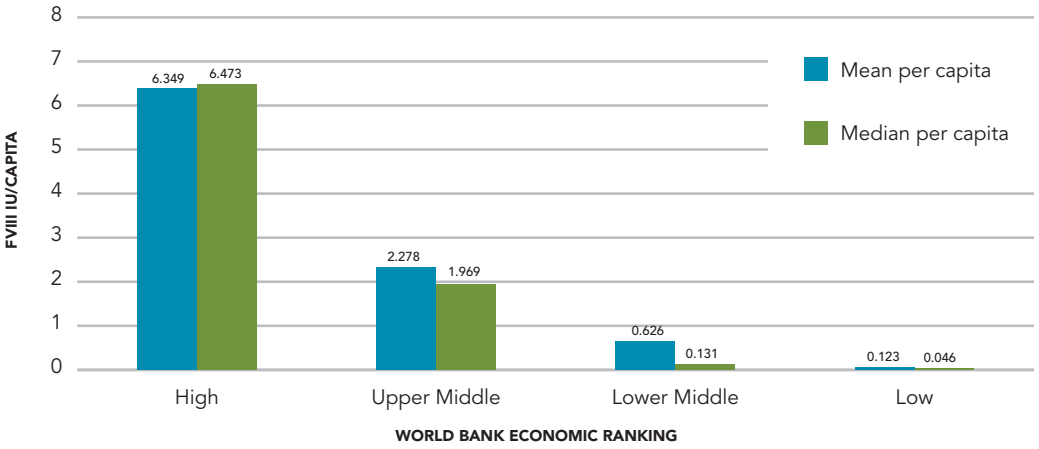
Total FVIII IU by gross national income



Economic category based on The World Bank Group 2020 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,045; C lower middle income, $1,046–$4,095; B upper middle income, $4,096–$12,695; and A high income, $12,695 or more.

FIGURE E. **Mean and median global factor VIII per capita 2020**

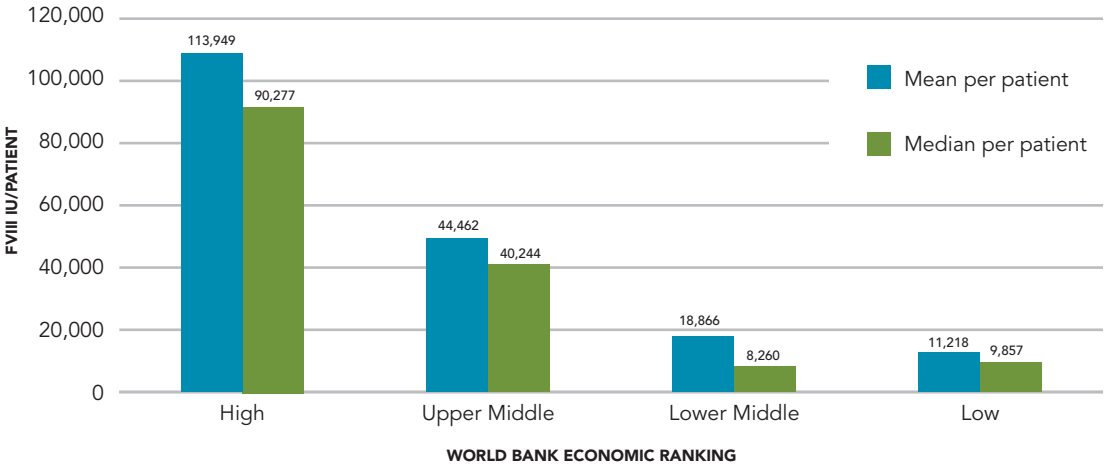
(Data from 101 countries.)



Economic category based on The World Bank Group 2020 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,045; C lower middle income, $1,046–$4,095; B upper middle income, $4,096–$12,695; and A high income, $12,695 or more.

FIGURE F. **Mean and median global factor FVIII per patient 2020**

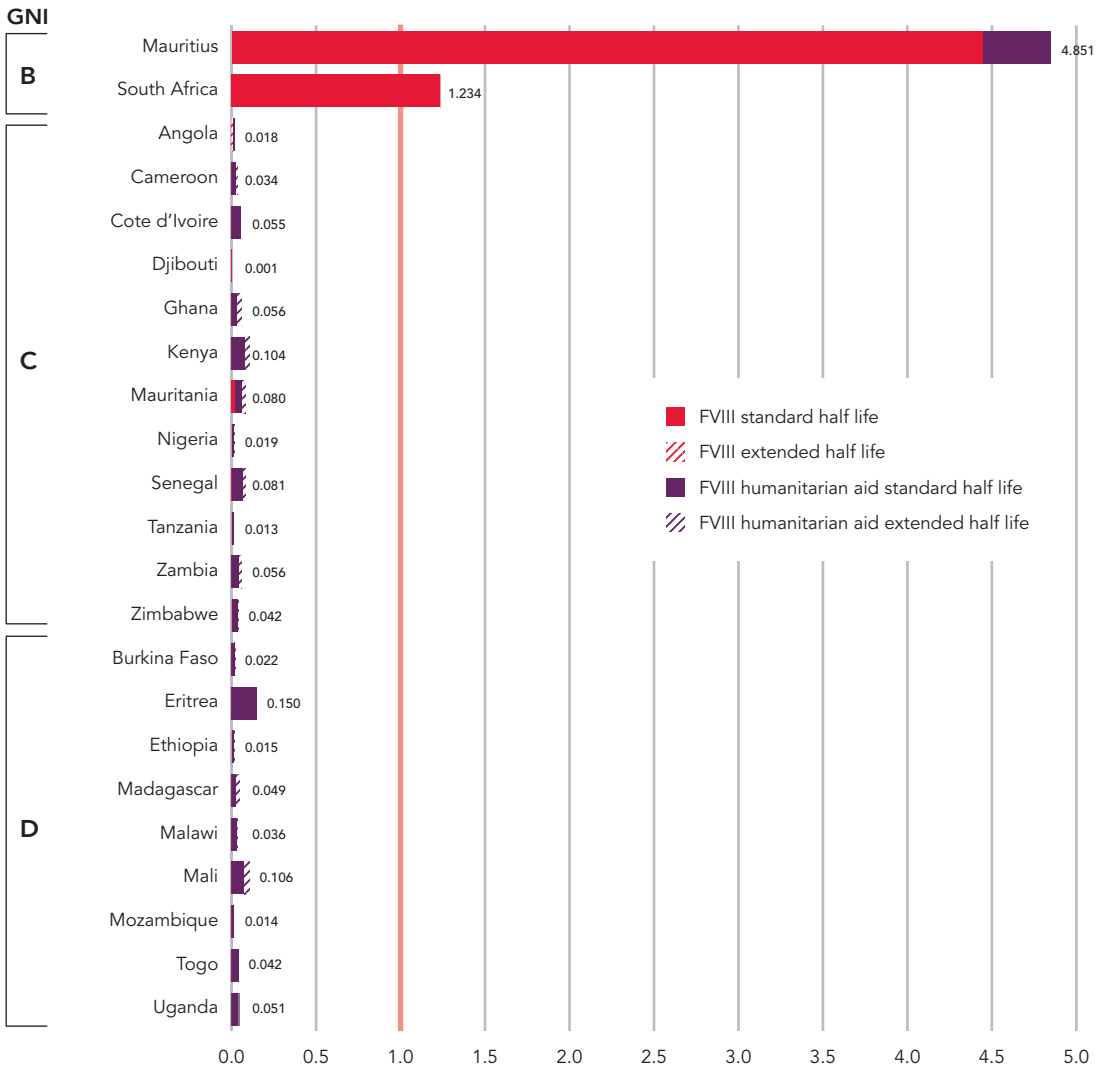
(Data from 101 countries.)



Economic category based on The World Bank Group 2020 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,045; C lower middle income, $1,046–$4,095; B upper middle income, $4,096–$12,695; and A high income, $12,695 or more.

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

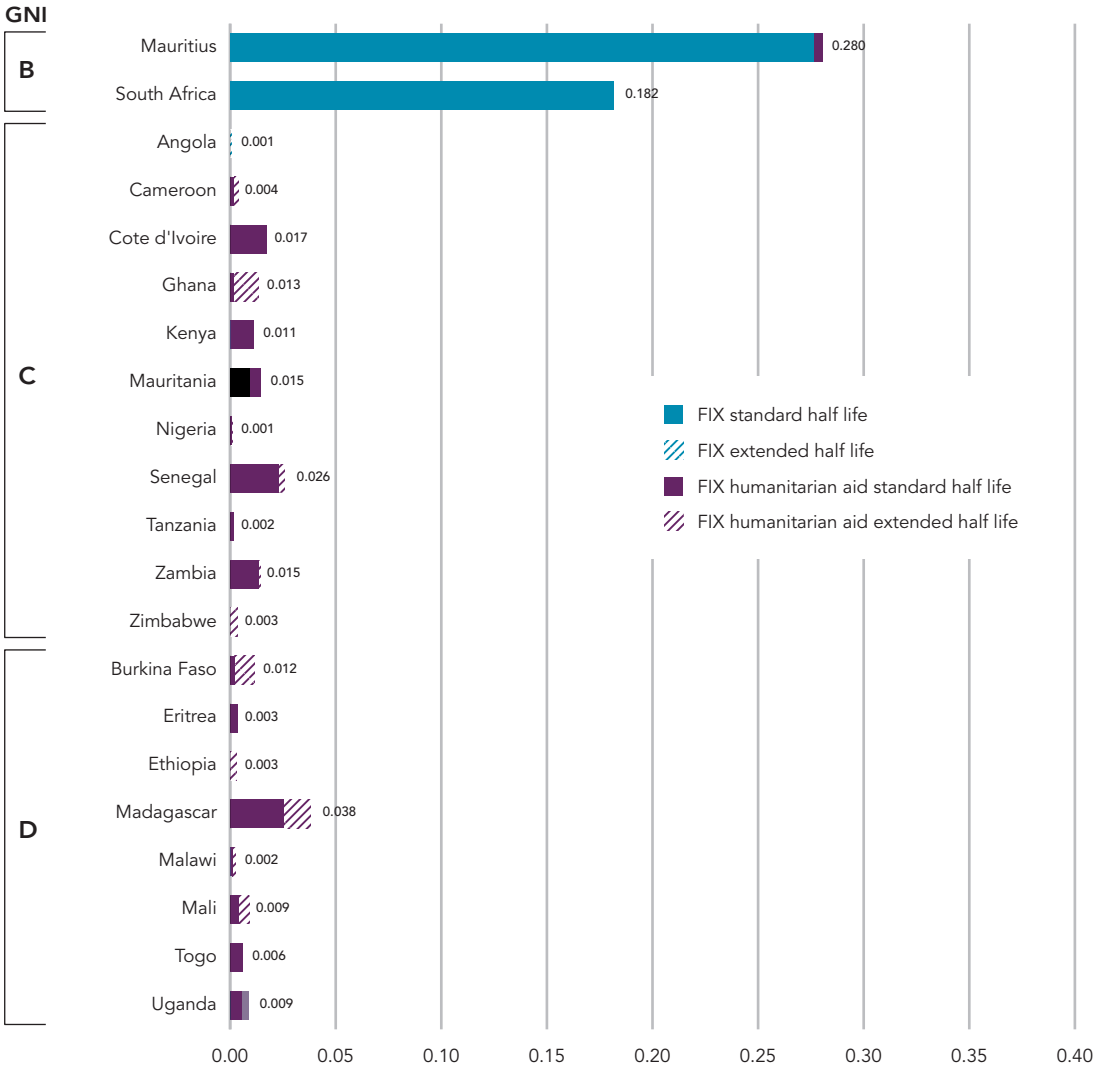
FIGURE G1a. **Mean per capita factor VIII use in 2020 – regional and GNI comparisons of IU/total population: Africa**



Economic category based on The World Bank Group 2020 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,045; C lower middle income, $1,046–$4,095; B upper middle income, $4,096–$12,695; and A high income, $12,695 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure G. 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 2020 questionnaire are included in Figure G 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.

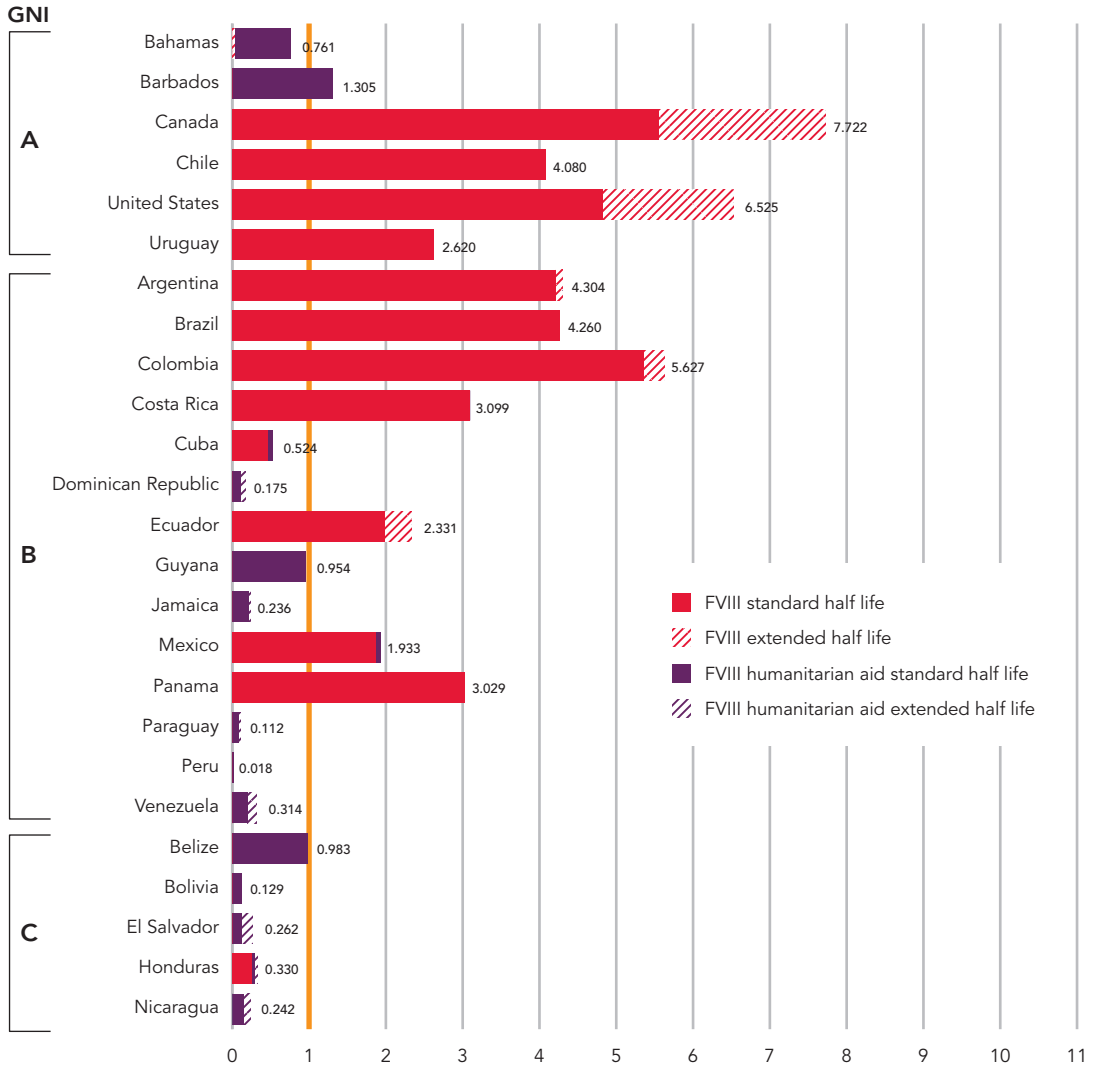
FIGURE G1b. **Mean per capita factor IX use in 2020 – regional and GNI comparisons of IU/total population: Africa**



Economic category based on The World Bank Group 2020 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,045; C lower middle income, $1,046–$4,095; B upper middle income, $4,096–$12,695; and A high income, $12,695 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure G. Only countries that provided product use data in the 2020 questionnaire are included in Figure G 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.

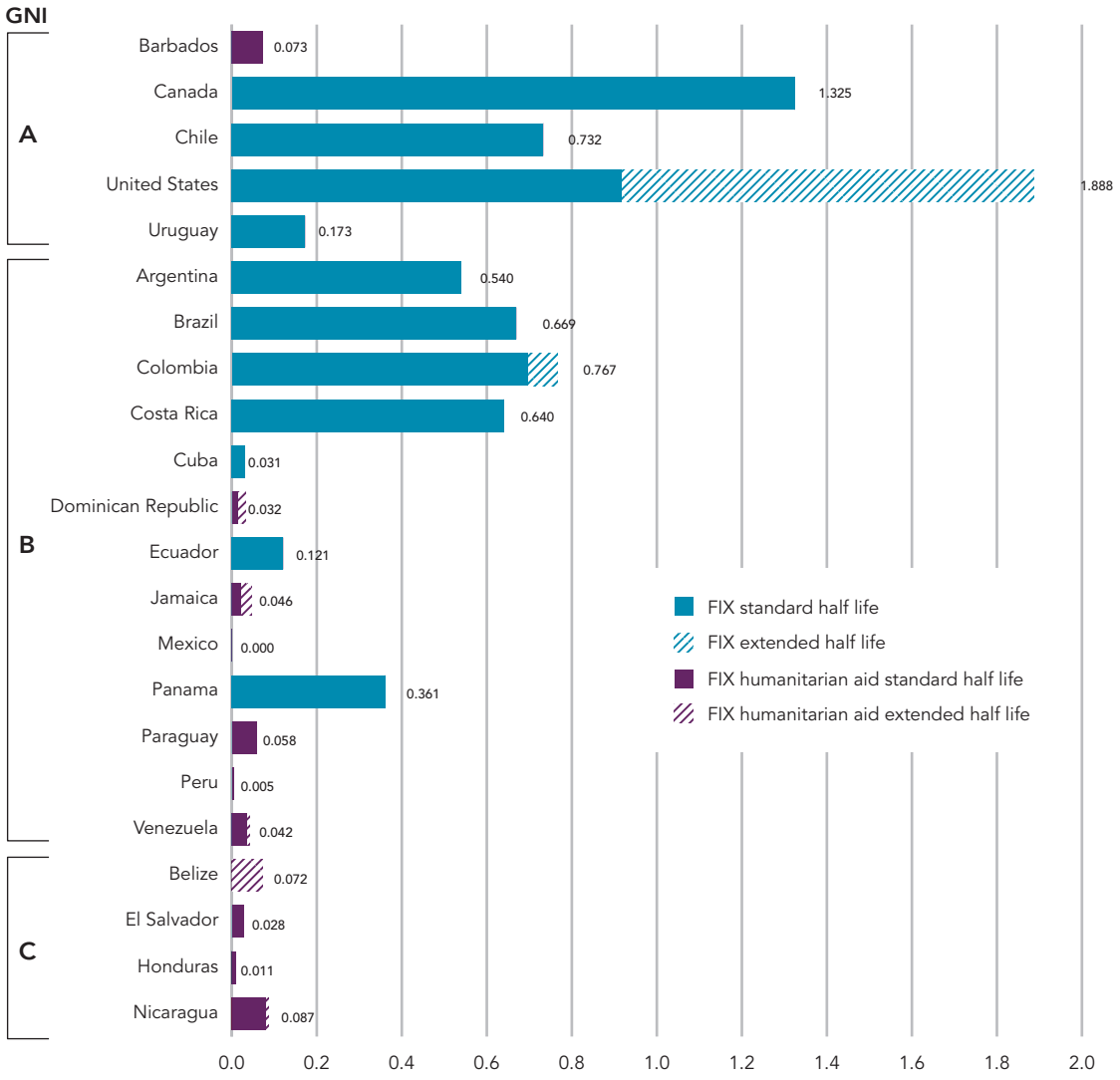
FIGURE G2a. **Mean per capita factor VIII use in 2020 – regional and GNI comparisons of IU/total population: Americas**



Economic category based on The World Bank Group 2020 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,045; C lower middle income, $1,046–$4,095; B upper middle income, $4,096–$12,695; and A high income, $12,695 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure G. 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 2020 questionnaire are included in Figure G 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.

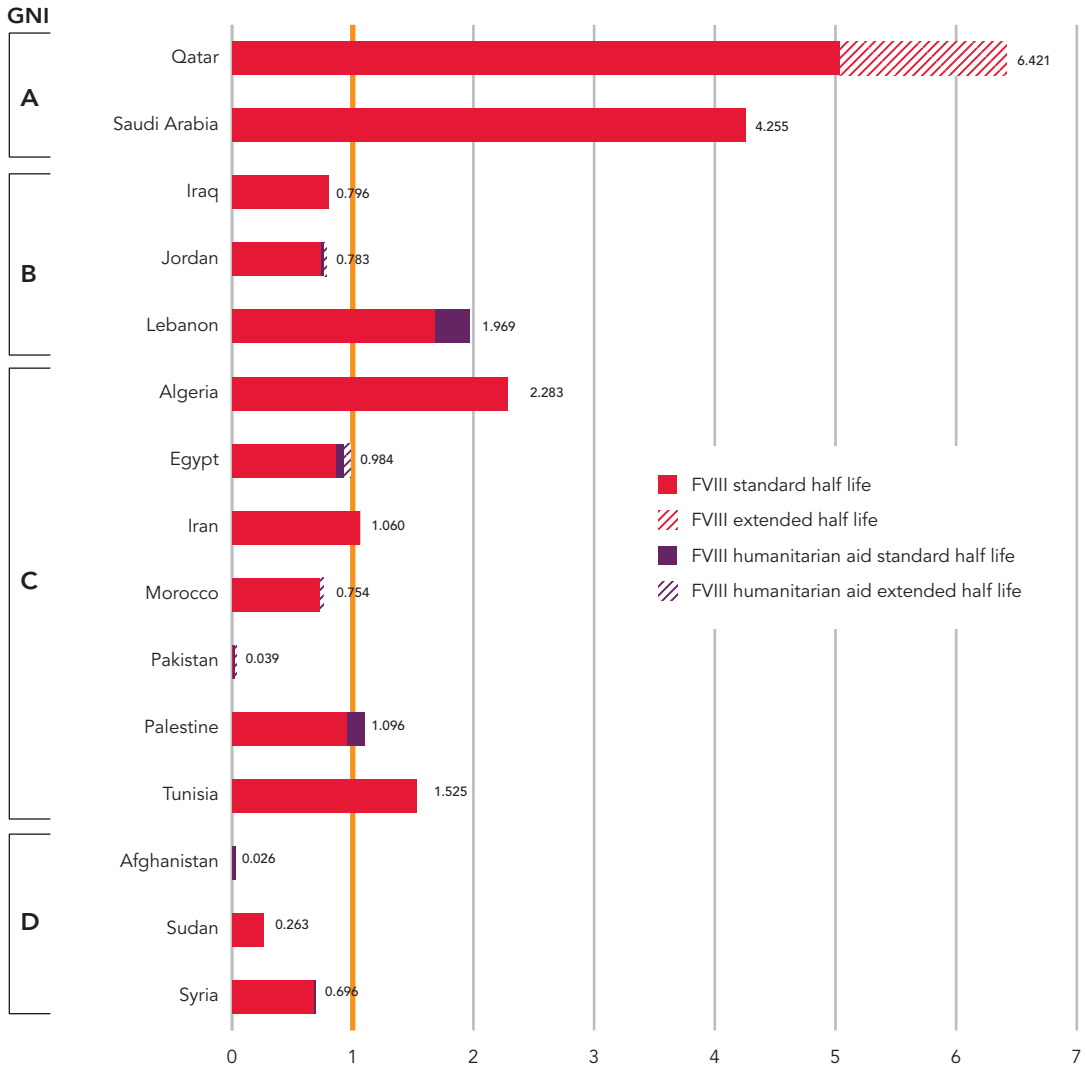
FIGURE G2b. **Mean per capita factor IX use in 2020 – regional and GNI comparisons of IU/total population: Americas**



Economic category based on The World Bank Group 2020 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,045; C lower middle income, $1,046–$4,095; B upper middle income, $4,096–$12,695; and A high income, $12,695 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure G. Only countries that provided product use data in the 2020 questionnaire are included in Figure G 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.

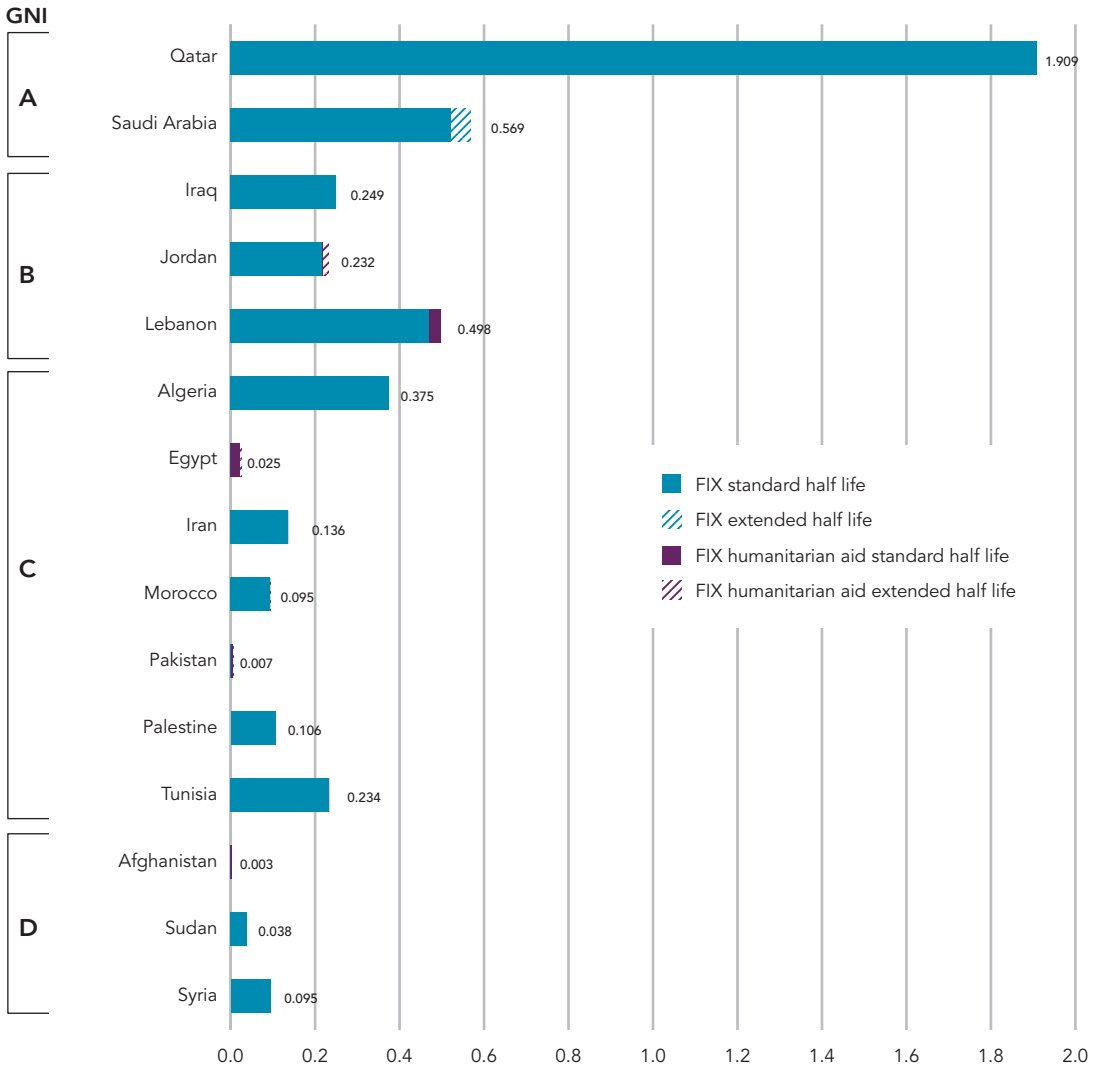
FIGURE G3a. **Mean per capita factor VIII use in 2020 – regional and GNI comparisons of IU/total population: Eastern Mediterranean**



Economic category based on The World Bank Group 2020 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,045; C lower middle income, $1,046–$4,095; B upper middle income, $4,096–$12,695; and A high income, $12,695 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure G. 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 2020 questionnaire are included in Figure G 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.

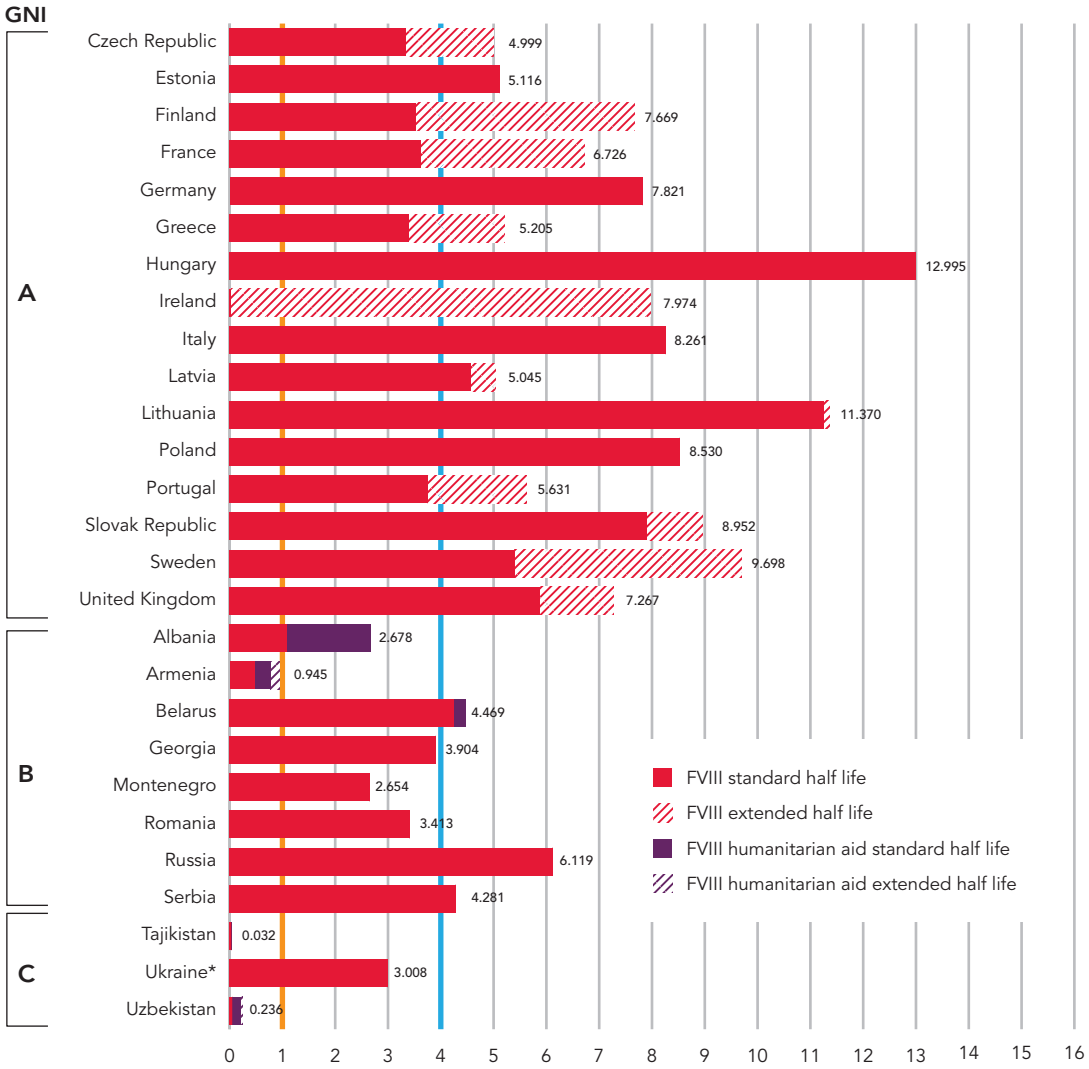
FIGURE G3b. **Mean per capita factor IX use in 2020 – regional and GNI comparisons of IU/total population: Eastern Mediterranean**



Economic category based on The World Bank Group 2020 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,045; C lower middle income, $1,046–$4,095; B upper middle income, $4,096–$12,695; and A high income, $12,695 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure G. Only countries that provided product use data in the 2020 questionnaire are included in Figure G 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 G4a. **Mean per capita factor VIII use in 2020 – regional and GNI comparisons of IU/total population: Europe**

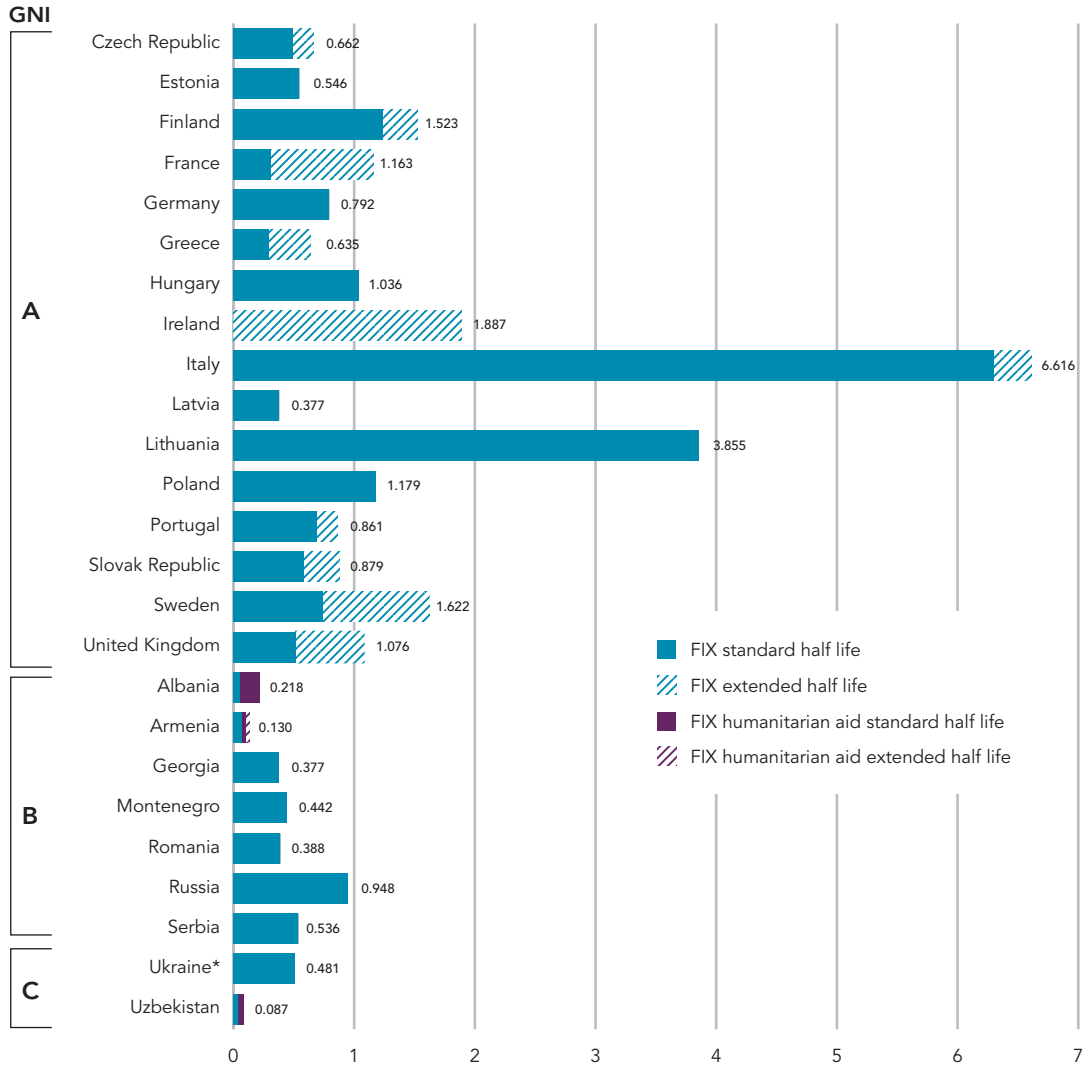


Economic category based on The World Bank Group 2020 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,045; C lower middle income, $1,046–$4,095; B upper middle income, $4,096–$12,695; and A high income, $12,695 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure G. 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 2020 questionnaire are included in Figure G 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.

** Data updated after publication. These updates are not reflected in any other calculations or summary tables in this report.*

FIGURE G4b. **Mean per capita factor IX use in 2020 – regional and GNI comparisons of IU/total population: Europe**

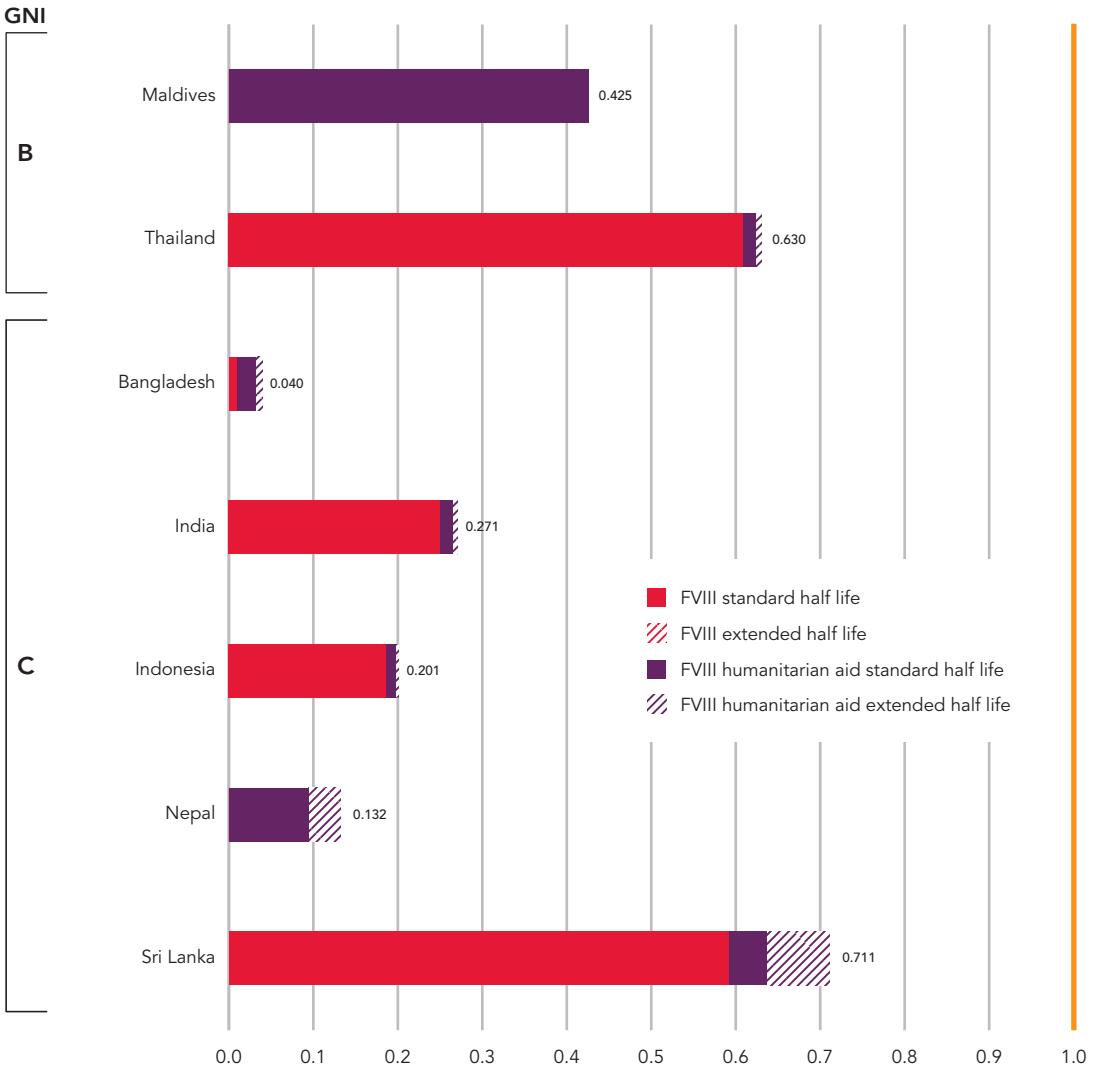


Economic category based on The World Bank Group 2020 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,045; C lower middle income, $1,046–$4,095; B upper middle income, $4,096–$12,695; and A high income, $12,695 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure G. Only countries that provided product use data in the 2020 questionnaire are included in Figure G 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.

** Data updated after publication. These updates are not reflected in any other calculations or summary tables in this report.*

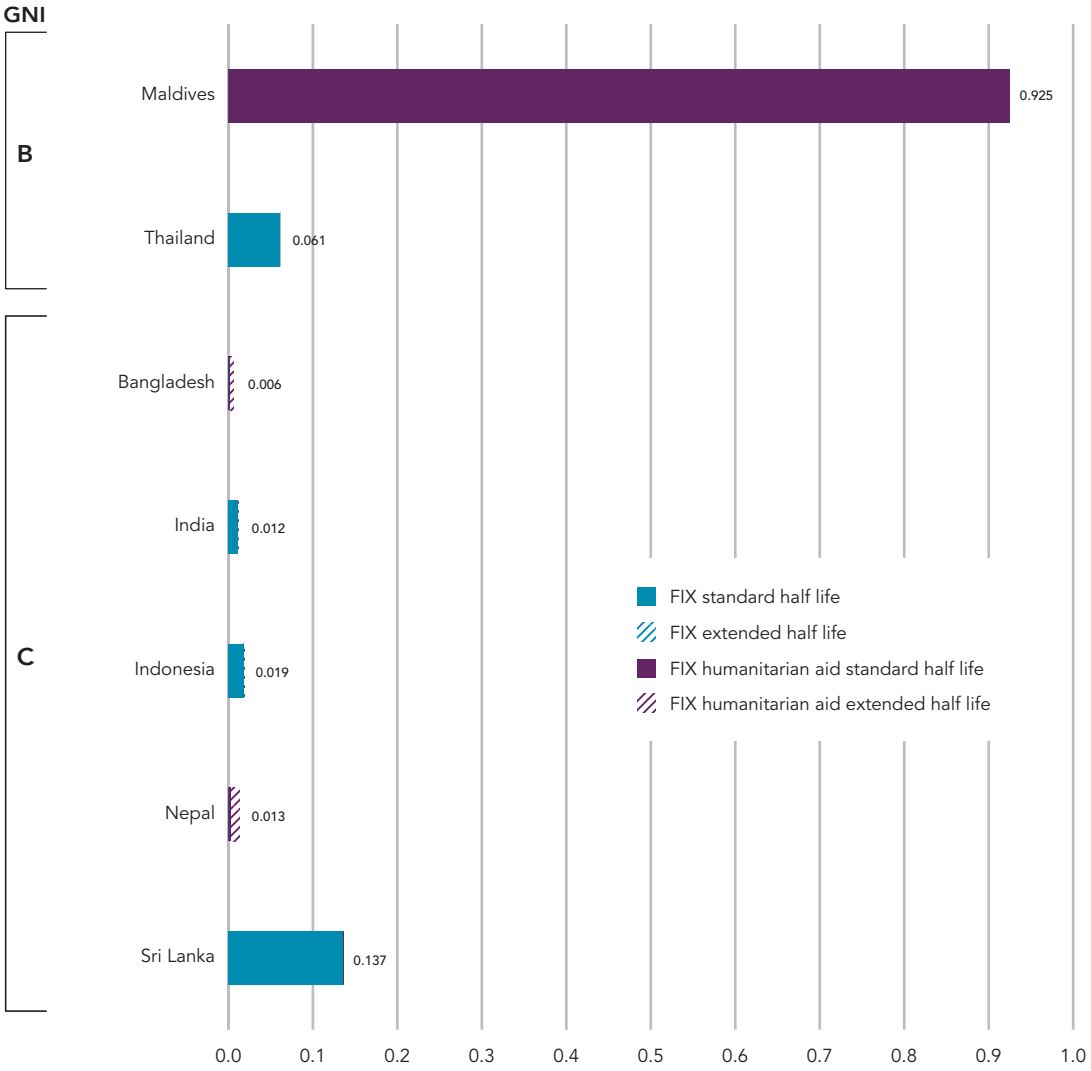
FIGURE G5a. **Mean per capita factor VIII use in 2020 – regional and GNI comparisons of IU/total population: South-East Asia**



Economic category based on The World Bank Group 2020 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,045; C lower middle income, $1,046–$4,095; B upper middle income, $4,096–$12,695; and A high income, $12,695 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure G. 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 2020 questionnaire are included in Figure G 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.

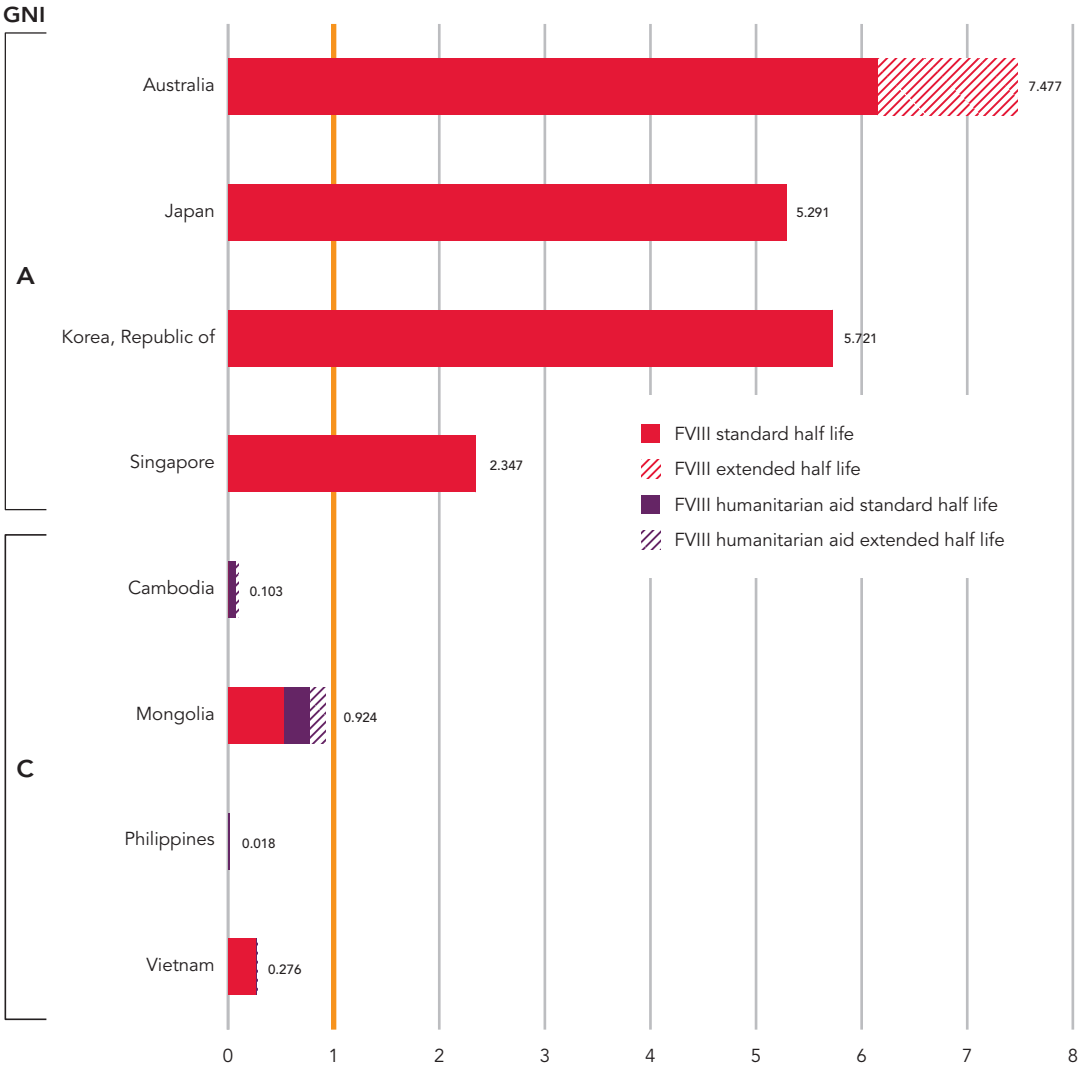
FIGURE G5b. **Mean per capita factor IX use in 2020 – regional and GNI comparisons of IU/total population: South-East Asia**



Economic category based on The World Bank Group 2020 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,045; C lower middle income, $1,046–$4,095; B upper middle income, $4,096–$12,695; and A high income, $12,695 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure G. Only countries that provided product use data in the 2020 questionnaire are included in Figure G 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.

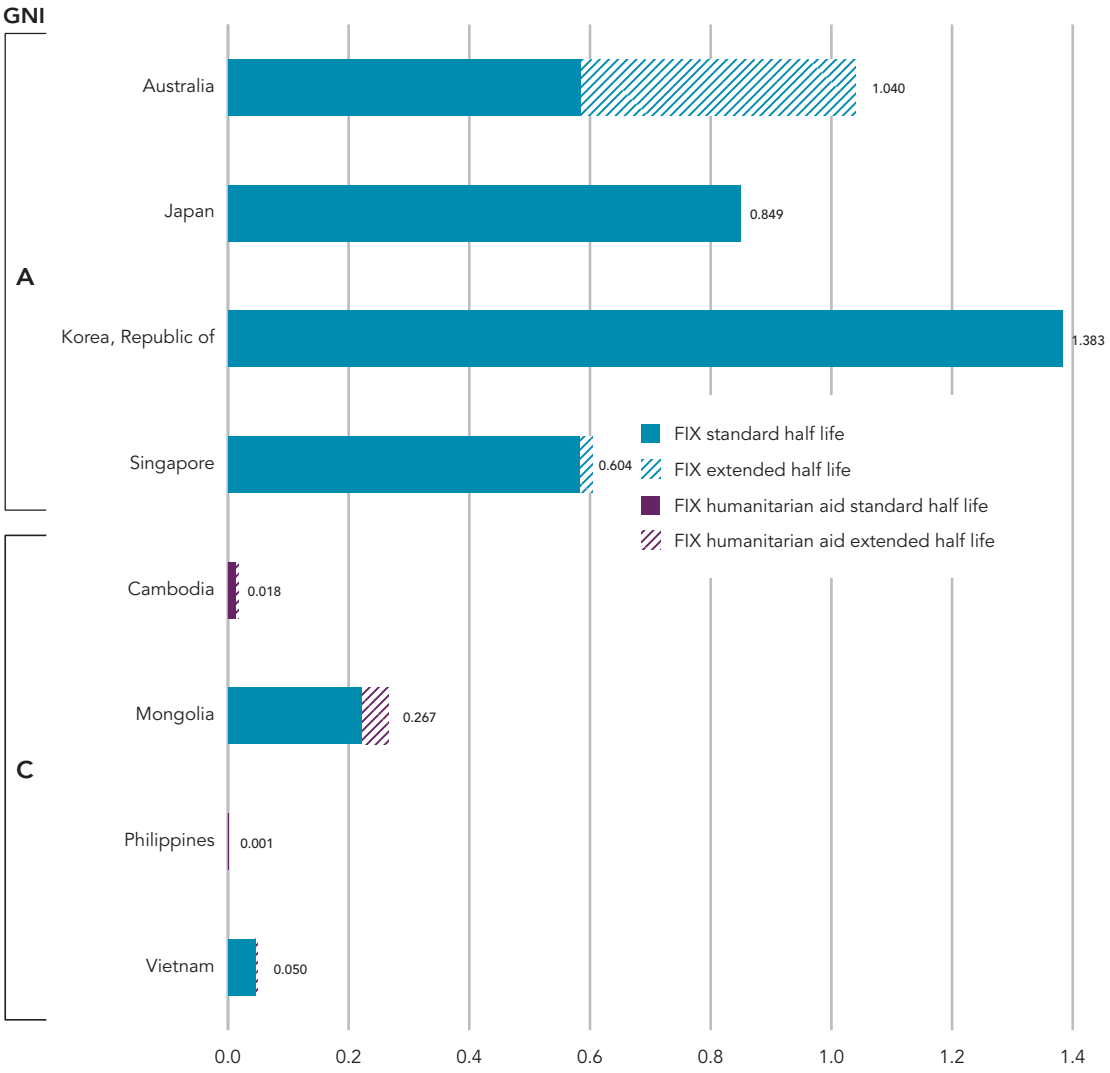
FIGURE G6a. **Mean per capita factor VIII use in 2020 – regional and GNI comparisons of IU/total population: Western Pacific**



Economic category based on The World Bank Group 2020 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,045; C lower middle income, $1,046–$4,095; B upper middle income, $4,096–$12,695; and A high income, $12,695 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure G. 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 2020 questionnaire are included in Figure G 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 G6b. **Mean per capita factor IX use in 2020 – regional and GNI comparisons of IU/total population: Western Pacific**



Economic category based on The World Bank Group 2020 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,045; C lower middle income, $1,046–$4,095; B upper middle income, $4,096–$12,695; and A high income, $12,695 or more.

PLEASE NOTE: The x-axis showing the number of IU/capita is different in each graph of Figure G. Only countries that provided product use data in the 2020 questionnaire are included in Figure G 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 H. **Data source**

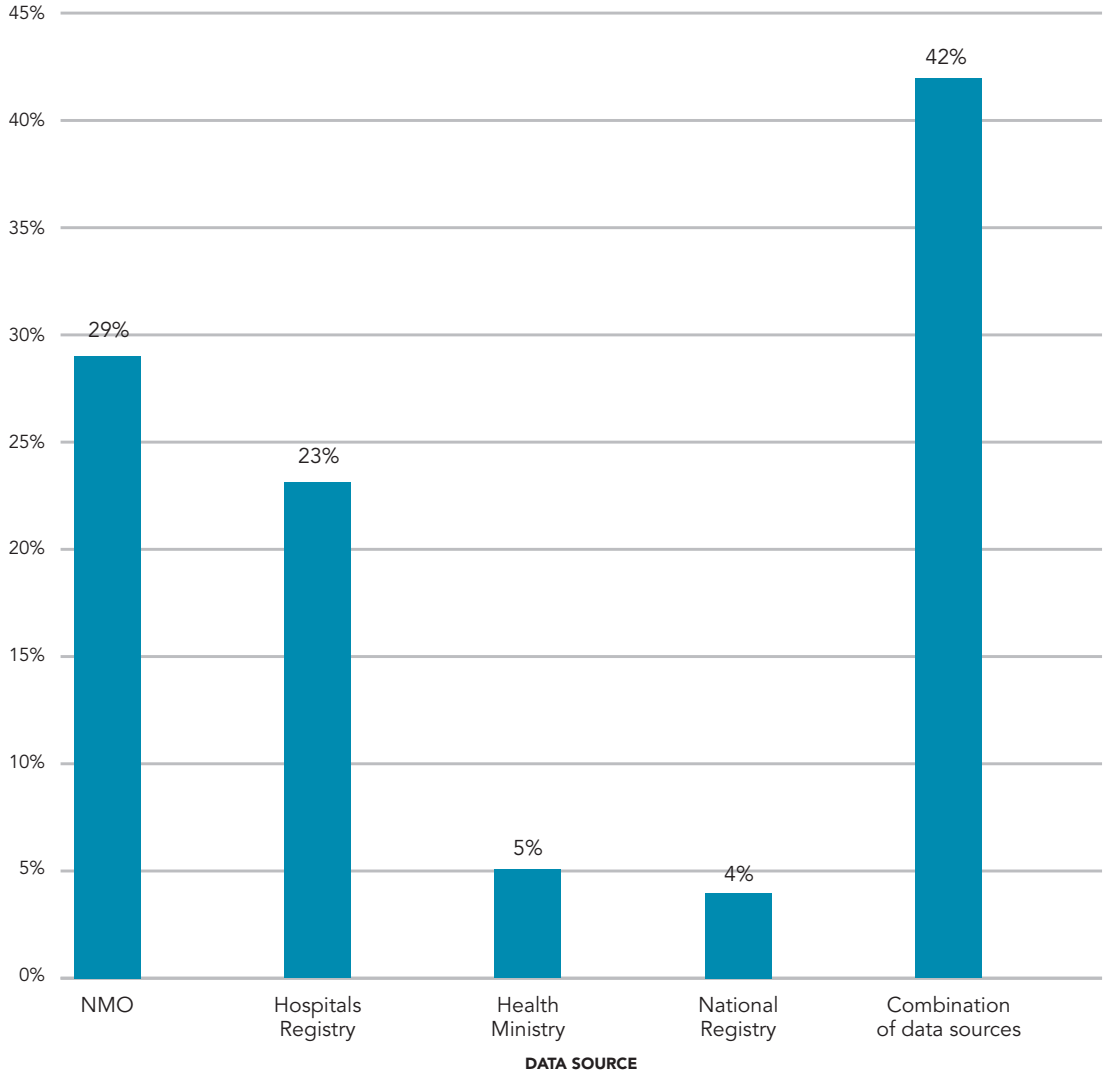
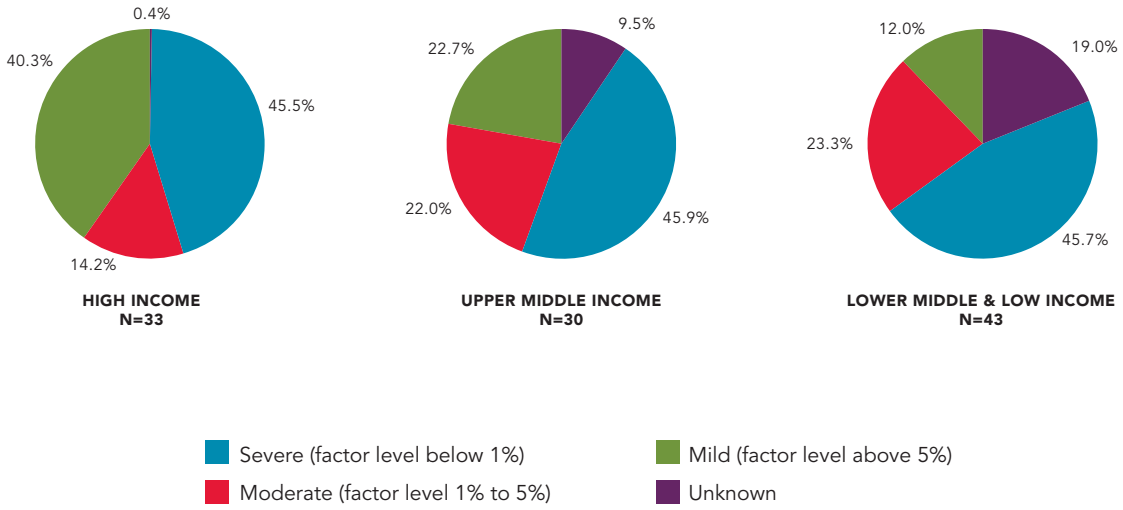


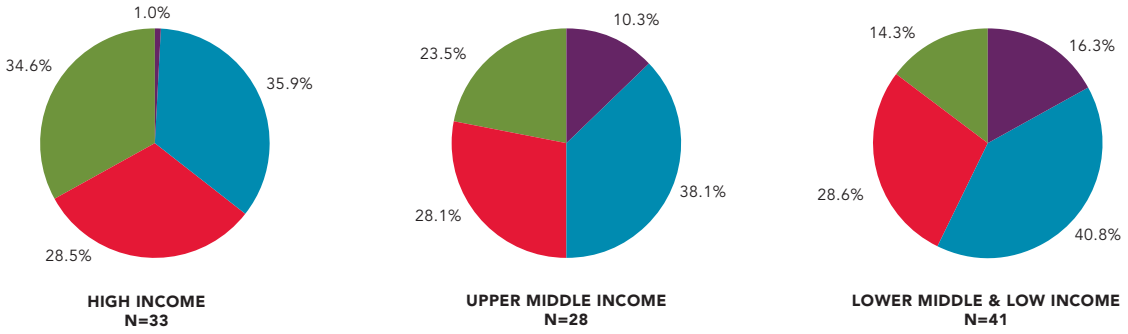
FIGURE I1. **Severity of hemophilia in males by GNI**

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

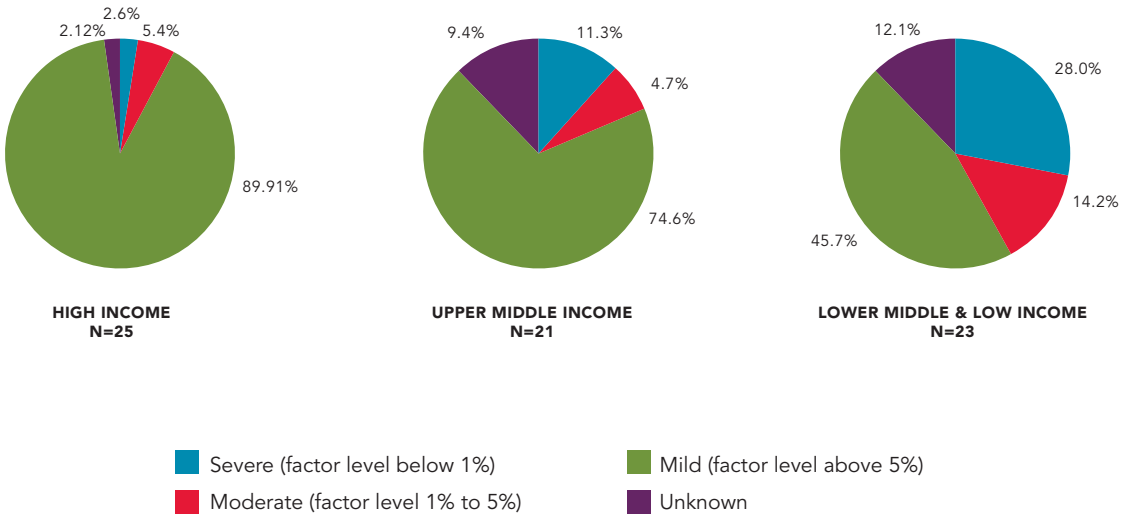


Economic category based on The World Bank Group 2020 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,045; C lower middle income, $1,046–$4,095; B upper middle income, $4,096–$12,695; and A high income, $12,695 or more.

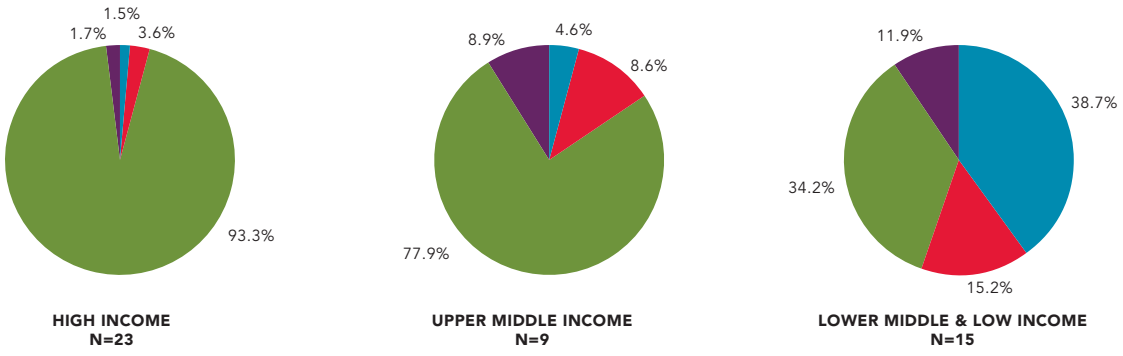
FIGURE I2. **Severity of hemophilia in females–by GNI**

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 2020 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,045; C lower middle income, $1,046–$4,095; B upper middle income, $4,096–$12,695; and A high income, $12,695 or more.

TABLE 6. **Population statistics**

Please note: in all of the population charts a 0 indicates that the member organization reported the number zero and "Not Known" means that the member organization reported that they do not know the answer.

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	38,928,341	529	2	3
Albania	2,837,743	243	7	8
Algeria	43,851,043	2,546	526	841
Angola	32,866,268	85	Not Known	1
Argentina	45,376,763	2,814	397	10
Armenia	2,963,234	222	15	61
Australia	25,687,041	2,827	2,324	994
Austria	8,917,205	854	Not Known	Not Known
Bahamas	393,248	10	2	0
Bangladesh	164,689,383	2,233	5	5
Barbados	287,371	27	5	3
Belarus	9,398,861	617	194	53
Belgium	11,555,997	1,309	2,202	560
Belize	397,621	19	Not Known	Not Known
Bolivia	11,673,029	180	3	Not Known
Botswana	2,351,625	51	7	0
Brazil	212,559,409	13,149	9,768	4,009
Burkina Faso	20,903,278	120	0	0
Cambodia	16,718,971	249	7	7
Cameroon	26,545,864	199	5	31
Canada	38,005,238	3,924	4,709	2,459
Chile	19,116,209	1,793	708	884
Colombia	50,882,884	3,834	3,446	782
Costa Rica	5,094,114	226	93	86
Cote d'Ivoire	26,378,275	125	3	3
Cuba	11,326,616	496	473	3,705
Czech Republic	10,698,896	1,037	779	153
Djibouti	988,002	20	2	7
Dominican Republic	10,847,904	548	52	59

Country	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Ecuador	17,643,060	1,708	99	7
Egypt	102,334,403	6,233	614	1,408
El Salvador	6,486,201	196	2	0
Eritrea	3,546,421	67	Not Known	Not Known
Estonia	1,331,057	121	128	126
Ethiopia	114,963,583	355	0	0
Finland	5,530,719	256	563	Not Known
France	67,391,582	8,661	2,992	1,127
Georgia	3,714,000	339	55	48
Germany	83,240,525	4,658	3,498	Not Known
Ghana	31,072,945	397	11	Not Known
Greece	10,715,549	1,016	1,210	560
Guyana	786,559	23	Not Known	Not Known
Honduras	9,904,608	384	21	3
Hungary	9,749,763	1,119	1,418	635
India	1,380,004,385	22,594	743	507
Indonesia	273,523,621	2,797	20	Not Known
Iran	83,992,953	10,352	1,755	3,790
Iraq	40,222,503	2,446	671	553
Ireland	4,994,724	899	1,762	1,421
Israel	9,216,900	735	175	184
Italy	59,554,023	4,991	3,245	2,315
Jamaica	2,961,161	74	3	8
Japan	125,836,021	6,738	1,438	437
Jordan	10,203,140	460	263	255
Kenya	53,771,300	731	37	16
Korea, Republic of	51,780,579	2,193	152	195
Latvia	1,901,548	101	71	18
Lebanon	6,825,442	231	178	73
Lesotho	2,142,252	31	Not Known	Not Known
Lithuania	2,794,700	182	305	17
Madagascar	27,691,019	136	2	14
Malawi	19,129,955	83	Not Known	Not Known
Malaysia	32,365,998	1,140	133	84
Maldives	540,542	19	Not Known	Not Known
Mali	20,250,834	150	23	16

Country	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Malta	525,285	37	46	Not Known
Mauritania	4,649,660	88	1	1
Mauritius	1,265,740	91	1	8
Mexico	128,932,753	5,852	355	65
Mongolia	3,278,292	115	14	Not Known
Montenegro	621,718	45	3	5
Morocco	36,910,558	991	173	149
Mozambique	31,255,435	264	4	6
Namibia	2,961,161	71	Not Known	4
Nepal	29,136,808	729	9	35
Netherlands	17,441,139	1,498	460	120
New Zealand	5,084,300	318	90	41
Nicaragua	6,624,554	422	60	2
Nigeria	206,139,587	630	13	Not Known
Norway	5,379,475	440	601	76
Pakistan	220,892,331	2,459	389	157
Palestine	4,803,269	352	59	137
Panama	4,314,768	318	521	104
Paraguay	7,132,530	296	4	39
Peru	32,971,846	1,002	209	Not Known
Philippines	109,581,085	1,604	46	Not Known
Poland	37,950,802	3,089	2,250	995
Portugal	10,305,564	935	911	935
Qatar	2,881,060	60	44	17
Romania	19,286,123	1,825	325	10
Russia	144,104,080	8,141	2,738	Not Known
Saudi Arabia	34,813,867	1,067	396	690
Senegal	16,743,930	298	13	15
Serbia	6,908,224	557	317	74
Singapore	5,685,807	270	93	80
Slovak Republic	5,458,827	630	765	1,344
Slovenia	2,100,126	254	189	11
South Africa	59,308,690	2,365	659	219
Spain	47,351,567	4,164	714	109
Sri Lanka	21,919,000	1,136	67	58
Sudan	43,849,269	1,331	367	454

Country	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Suriname	586,634	15	3	0
Sweden	10,353,442	1,011	908	Not Known
Switzerland	8,636,896	571	149	68
Syria	17,500,657	957	133	209
Tajikistan	9,537,642	590	Not Known	32
Tanzania	59,734,213	168	6	2
Thailand	69,799,978	1,828	150	80
Togo	8,278,737	50	Not Known	Not Known
Tunisia	11,818,618	581	233	462
Uganda	45,741,000	303	3	1
Ukraine*	44,134,693	1,941	463	112
United Kingdom	67,215,293	8,509	11,183	12,171
United States	329,484,123	14,816	8,919	3,990
Uruguay	3,473,727	293	263	1
Uzbekistan	34,232,050	1,746	177	45
Venezuela	28,435,943	2,868	1,184	1,118
Vietnam	97,338,583	3,913	184	535
Zambia	18,383,956	198	5	0
Zimbabwe	14,862,927	175	1	Not Known

** Data updated after publication. These updates are not reflected in any other calculations or summary tables in this report.*

TABLE 7. **Distribution of reported bleeding disorders by country**

Please note: 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	481	48		2								3				
Albania	208	35	0	7					4	2		2				
Algeria	1,998	548		526	64	10	84	31	499	36	21	19	32	30	15	
Angola	74	11	0						1							
Argentina	2,428	386	0	397	0	0	0	1	2	0	1	1	0	2	0	3
Armenia	198	24		15	2		1	3	23	1	3	1	12	4	6	5
Australia	2,288	539	0	2,324	133	0	18	0	100	19	325	44	0	30	12	313
Austria	705	149														
Bahamas	7	2	1	2	0	0	0	0	0	0	0	0	0	0	0	0
Bangladesh	1,852	375	6	5	2		2					1				
Barbados	16	11	0	5			2	1								
Belarus	499	118		194	8				19		26					
Belgium	1,052	249	8	2,202	2	2	22	0	166	11	151	5	49	21	6	125
Belize	14	5														
Bolivia	146	34		3												
Botswana	43	8	0	7												
Brazil	10,984	2,165	0	9,768	149	21	278	50	1,684	158	336	87	0	614	112	520
Burkina Faso	93	27	0													
Cambodia	211	38	0	7								1				6
Cameroon	169	30	0	5					1		30					
Canada	3,223	701	0	4,709	181	18	89	0	563	60	542	60	0	35	71	840
Chile	1,566	172	55	708	0	0	17	7	377	18	47	5	3	7	4	399
Colombia	3,148	686	0	3,446	77	17	76	55	215	40	131	84	36	15	2	34
Costa Rica	183	43	0	93	4		2	13	46	12	7	2				
Cote d'Ivoire	108	17	0	3	0	0	0	0	1	2	0	0	0	0	0	0
Cuba	414	82	0	473	3	1	2	0	2	0	10	7	19	2	0	3,659
Czech Republic	898	139	0	779	0	4	12	0	83	6	30	1	17			
Djibouti	20	0	0	2	0	0	0	0	1	0	0	0	0	0	0	6
Dominican Republic	462	55	31	52	0	0	0	0	12	40	0	5	0	2	0	0
Ecuador	755	99	854	99					5			2				
Egypt	5,084	1,149		614	203	8	175	7	247	107	80	49	22	457	53	
El Salvador	173	23	0	2	0	0	0	0	0	0	0	0	0	0	0	0

Country	Hemophilia A	Hemophilia B	Hemophilia type unknown	VWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXIII	Bleeding disorder: type unkown	Glanzmann's thrombasthenia	Bernard-Soulier syndrome	Platelet disorders: other/ unknown
Eritrea	60	7	0													
Estonia	110	11		128	12	1	6	1	37	2	8		38		2	19
Ethiopia	163	33	159													
Finland	172	30	54	563												
France	6,987	1,674	0	2,992	42	1	59	21	218	31	255	34	0	234	67	165
Georgia	283	56		55	1		1		29	1		3		7		6
Germany	3,884	774		3,498												
Ghana	325	27	45	11												
Greece	831	185	0	1,210	38	2	34	2	190	13	105	11	0	17	12	136
Guyana	22	1														
Honduras	324	35	25	21								3				
Hungary	880	239		1,418	20	2	25	0	389	25	92	5		3	1	73
India	18,928	3,104	562	743	21	9	52	13	83	52	37	129		89		22
Indonesia	2,334	353	110	20												
Iran	5,415	1,147	3,790	1,755	168	28	281	257	915	234	303	282	257	628	107	330
Iraq	1,928	518		671	60	2	15	4	145	30	14	65		118	23	77
Ireland	671	228	0	1,762	96	3	186	1	273	162	277	13	0	14	4	392
Israel	628	107	0	175	5	0	9	14	90	9		8	0	44	5	
Italy	4,109	882		3,245		27	175	38	1,138	118	540	62	217			
Jamaica	66	5	3	3	0	0	0	0	0	5	0	0	0	1	0	2
Japan	5,533	1,205		1,438	97	7	50	9	122	24	50	78				
Jordan	353	107		263	1	4	12		51	21	37	17		112		
Kenya	589	142	0	37	0	0	0	0	3	1	0	0	0	0	0	12
Korea, Republic of	1,755	438	0	152	8	0	7	2	50	2	31	4	91			
Latvia	85	16		71			2		12	2				1	1	
Lebanon	182	49	0	178	35	0	9	1	7	6	5	4	0	1	0	5
Lesotho	29	2														
Lithuania	154	27	1	305					12	2						3
Madagascar	73	63		2	14											
Malawi	26	5	52													
Malaysia	959	181		133	2	2	3	0	27	9	11	6	2	16	2	4
Maldives	15	4														
Mali	136	14	0	23	1	0	0	0	1	0	0	1	12	0	0	1
Malta			37	46												
Mauritania	70	18	0	1										1		
Mauritius	82	9	0	1	0	0	0	0	4	1	0	0	1	2	0	0
Mexico	4,825	722	305	355	3	2	3	0	30	5	5	4	5	4	0	4

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
Mongolia	84	31		14												
Montenegro	41	4	0	3	0	0	0	0	1	0	1	3	0	0	0	0
Morocco	725	147	119	173	16	6	11	5	63	6	4	2		28	2	6
Mozambique	104	40	120	4			2	2	1			1				
Namibia	57	10	4											1	3	
Nepal	585	109	35	9			2	1	7	22		3				
Netherlands	1,310	188	0	460	11	5	7	1	21	2	15	12		16		30
New Zealand	270	48		90					6	3	11	3		2	1	15
Nicaragua	274	28	120	60	2	0	0	0	0	0	0	0	0	0	0	0
Nigeria	531	24	75	13												
Norway	346	94		601	3	2	4	0	37	5	2	5		13	5	
Pakistan	2,086	373	0	389	14	4	19	4	38	26	1	26	1	22	2	0
Palestine	292	60		59	0	7	4	1	2	16	0	2	96	9		
Panama	281	37	0	521					10	16				11	1	66
Paraguay	267	29	0	4					38	1						
Peru	852	150		209												
Philippines	1,187	207	210	46												
Poland	2,605	484	0	2,250	155	1	33	3	347	29	79	13	0	30	12	293
Portugal	742	193		911	33	2	26	6	346	21	175	10	24	33	28	231
Qatar	51	9	0	44	0	0	1	0	3	1	0	2	0	2	5	3
Romania	1,615	210		325	2			1	3		2		2			
Russia	6,867	1,274		2,738												
Saudi Arabia	871	195	1	396	12	21	42	6	71	47	21	97	3	262	30	78
Senegal	261	37		13	1	0	1	0	4	1	0	1		2		5
Serbia	469	88	0	317	9	0	4	2	39	1	11	5	1	0	2	0
Singapore	224	46	0	93			15		9		51	5				
Slovak Republic	546	84	0	765	123	0	83	1	970	39	60	8	0	10	15	35
Slovenia	224	30	0	189	4	0	0	0	0	0	0	0	0	7	0	0
South Africa	1,986	379	0	659	7	0	44	5	18	9	27	8	0	22	28	51
Spain	1,802	280	2,082	714	15	3	11		28	8	26	17		1		
Sri Lanka	915	221		67	1	2	10	1	3	2	10	9		11		9
Sudan	1,072	259		367	57	1	59	4	50	30	8	28		18	16	183
Suriname	15	0	0	3	0	0	0	0	0	0	0	0	0			
Sweden	802	209		908												
Switzerland	458	113	0	149	14		0	0	14	4	17	13		6	0	
Syria	855	98	4	133	23	0	18	34	42	4			1	49	8	30

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
Tajikistan	541	37	12										14	18		
Tanzania	125	20	23	6						2						
Thailand	1,615	213		150	0	1	8	2	27	2	3	2		13	11	11
Togo	39	7	4													
Tunisia	463	118	0	233	46	0	19	8	139	16	119	40	5	50	8	12
Uganda	261	40	2	3					1							
Ukraine*	1,651	290		463												
United Kingdom	6,940	1,569	0	11,183	942	17	259	28	1,885	320	3,754	81	1,360	149	104	3,272
United States	11,790	3,026	0	8,919	158	37	102	8	807	121	474	91	2,005	150	37	
Uruguay	238	39	16	263					1							
Uzbekistan	1,559	177	10	177					12		6	6		19	2	
Venezuela	2,266	602	0	1,184	23	67	42	29	180	112	402	16	18	27	5	197
Vietnam	3,228	685	0	184	24	6	19	16	78	28	28	20	3	107	3	203
Zambia	135	27	36	5		0	0	0	0	0	0	0	0	0	0	0
Zimbabwe	161	14		1												

** Data updated after publication. These updates are not reflected in any other calculations or summary tables in this report.*

TABLE 8. **Sex distribution**

This table provides the number of males and females with each bleeding disorder from the countries that have reported sex data. Total percentages may not add up to 100% as some countries have not provided complete information on sex distribution of their patients.

Disorders	Countries reporting	Total patients identifed	Male	Percent male	Female	Percent female	Sex not known	Percent not known
Hemophilia A	**119**	165,379	146,246	**88**	5,636	**3**	9,917	**6**
Hemophilia B	**119**	33,076	28,814	**87**	1,795	**5**	1,926	**6**
Hemophilia type unknown	**84**	11,159	5,889	**53**	2,050	**18**	106	**1**
von Willebrand disease (VWD)	**107**	84,197	28,706	**34**	47,024	**56**	6,761	**8**
Factor I Deficiency	**70**	3,147	1,394	**44**	1,688	**54**	15	**0**
Factor II Deficiency	**64**	353	179	**51**	167	**47**	0	**0**
Factor V Deficiency	**74**	2,554	1,197	**47**	1,305	**51**	0	**0**
Factor V+VIII Deficiency	**69**	699	366	**52**	315	**45**	0	**0**
Factor VII Deficiency	**85**	13,178	6,446	**49**	6,464	**49**	18	**0**
Factor X Deficiency	**76**	2,161	1,112	**51**	1,002	**46**	4	**0**
Factor XI Deficiency	**71**	8,817	3,763	**43**	4,865	**55**	18	**0**
Factor XIII Deficiency	**77**	1,637	884	**54**	669	**41**	13	**1**
Bleeding disoder: type unknown	**54**	4,346	1,384	**32**	2,938	**68**	2	**0**
Platelet disorder: Glanzmann's Thrombasthenia	**68**	3,599	1,699	**47**	1,680	**47**	16	**0**
Platelet disorder: Bernard-Soulier Syndrome	**59**	833	346	**42**	424	**51**	44	**5**
Platelet Disorders: Other/Unknown	**57**	11,891	2,735	**23**	4,921	**41**	4,199	**35**

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 9. **Number of inhibitor cases in Hemophilia A and B**

(98 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
Albania	18	0	2	0
Algeria	122	12	0	0
Argentina	63	1	7	0
Australia	67	8	5	0
Austria	18	2	0	0
Bahamas	1	0	0	0
Bangladesh	6	0	4	0
Barbados	1		1	
Belarus	50		4	
Belize	0		0	
Bolivia	3			
Botswana	3	0	0	0
Brazil	376	80	22	7
Burkina Faso	1	0	0	0
Cambodia	7	0	0	0
Cameroon	12			
Canada	72	8	3	0
Chile	31	4	3	1
Colombia	216	12	23	0
Costa Rica	22	22	0	0
Cote d'Ivoire	4	0	1	0
Cuba	35	1	0	0
Czech Republic	22	1	2	0
Dominican Republic	19		6	
Ecuador	21	2		
Egypt	443	103	2	0
El Salvador	18	0	4	0

	Hemophilia A active inhibitors	Hemophilia A new cases inhibitors	Hemophilia B active inhibitors	Hemophilia B new cases inhibitors
Eritrea	0	0	0	0
Estonia	4	0	0	0
Finland	15	5	1	1
France	196	10	16	1
Georgia	10			
Germany	91		5	
Ghana	0	0	0	0
Greece	20	2	2	0
Honduras	12	0	0	0
Hungary	23	1	0	0
India	564	83	24	8
Indonesia	51		0	
Iran	352	6	35	7
Iraq	202	2	8	1
Ireland	12	0	3	0
Israel	19	3	2	0
Jamaica	11	4	0	0
Jordan	26		1	
Kenya	8	1	0	0
Korea, Republic of	76		6	
Lebanon	8	1	0	0
Lesotho	1	1		
Lithuania	7			
Madagascar	3	0	1	0
Malaysia	104	6	7	0
Maldives	1	1		
Mali	4	2	0	0
Mauritius	1	1	0	0
Montenegro	1	0	0	0
Morocco	103	12	3	0
Mozambique	5	2	2	
Nepal	17	1		
New Zealand	8	0	0	0
Nicaragua	5	0	0	0
Nigeria	17	17		
Norway	12	0	0	0

	Hemophilia A active inhibitors	Hemophilia A new cases inhibitors	Hemophilia B active inhibitors	Hemophilia B new cases inhibitors
Pakistan	30	3	1	0
Palestine	3		0	
Panama	6	1	0	0
Paraguay	0	10		
Philippines	42	8	2	0
Poland	102			
Portugal	31	5	1	0
Qatar	2	1	0	0
Romania	94			
Saudi Arabia	117	5	3	0
Senegal	13	2	0	
Serbia	16	1	0	0
Singapore	5	1	0	0
Slovak Republic	6	0	1	0
Slovenia	4	0	1	1
South Africa	178	5	13	1
Sri Lanka	88	13		
Sudan	8	2		
Suriname	0	0	0	0
Sweden	29	3	3	3
Switzerland	13	0	0	0
Syria	72	3	1	0
Tajikistan	1			
Tanzania	4	13		
Thailand	100	18	2	0
Togo	1			
Tunisia	23	0	5	0
Uganda	6	6		
Ukraine*	110	4	6	0
United Kingdom	222	11	13	1
United States	753		65	
Uruguay	15		3	
Uzbekistan	29	3		
Venezuela	94	1	1	0
Vietnam	145	14	1	0
Zambia	0	0	0	0

** Data updated after publication. These updates are not reflected in any other calculations or summary tables in this report.*

TABLE 10. **Age distribution: Hemophilia A**

(103 countries reported age data for hemophilia A)

	Hemophilia A	0–4	5–13	14–18	19–44	45+	Age not known
Afghanistan	481	4%	52%	20%	24%	0%	0%
Albania	208	1%	13%	9%	50%	27%	0%
Algeria	1,998	2%	20%	13%	50%	15%	0%
Angola	68	15%	53%	13%	18%	1%	0%
Argentina	2,428	2%	14%	9%	46%	26%	3%
Armenia	198	9%	24%	8%	38%	21%	0%
Australia	2,288	6%	15%	7%	38%	35%	0%
Austria	705	6%	10%	9%	44%	32%	0%
Bahamas	7	0%	14%	14%	57%	14%	0%
Bangladesh	1,852	14%	33%	19%	31%	3%	0%
Barbados	16	6%	13%	6%	44%	31%	0%
Belgium	1,052	2%	10%	8%	36%	43%	0%
Belize	14	7%	21%	14%	57%	0%	0%
Bolivia	146	15%	26%	14%	32%	4%	9%
Botswana	43	16%	30%	16%	35%	2%	0%
Brazil	10,984	5%	15%	9%	50%	21%	0%
Burkina Faso	93	26%	47%	12%	15%	0%	0%
Cambodia	211	4%	45%	22%	27%	0%	2%
Cameroon	169	11%	40%	31%	17%	2%	0%
Canada	3,223	3%	12%	8%	42%	36%	0%
Chile	1,566	3%	14%	11%	50%	21%	0%
Colombia	3,148	6%	11%	13%	59%	11%	0%
Costa Rica	183	5%	13%	13%	56%	13%	0%
Cote d'Ivoire	108	19%	31%	16%	29%	6%	0%
Czech Republic	898	6%	13%	6%	29%	24%	22%
Djibouti	20	30%	50%	5%	0%	15%	0%
Dominican Republic	462	3%	14%	9%	29%	7%	38%
Egypt	5,084	7%	38%	11%	36%	8%	0%
El Salvador	173	16%	25%	20%	25%	14%	0%
Eritrea	60	8%	25%	18%	43%	2%	3%
Estonia	110	9%	8%	5%	59%	18%	1%
Ethiopia	163	4%	38%	14%	42%	2%	0%
France	6,987	6%	15%	10%	40%	29%	0%
Georgia	283	6%	20%	7%	46%	22%	0%
Ghana	325	18%	49%	16%	13%	1%	3%

	Hemophilia A	0–4	5–13	14–18	19–44	45+	Age not known
Greece	831	4%	8%	5%	40%	42%	0%
Guyana	22	0%	36%	9%	41%	14%	0%
Honduras	324	10%	24%	14%	44%	2%	6%
Hungary	880	2%	8%	5%	35%	49%	0%
India	18,928	2%	14%	11%	43%	10%	20%
Indonesia	2,334	8%	32%	18%	39%	4%	1%
Iran	5,415	4%	13%	8%	55%	21%	0%
Iraq	1,928	22%	40%	20%	15%	3%	0%
Ireland	671	5%	17%	9%	37%	31%	0%
Israel	628	11%	17%	9%	40%	24%	0%
Italy	3,359	3%	13%	11%	21%	52%	0%
Jamaica	66	15%	12%	3%	44%	21%	5%
Kenya	589	17%	30%	27%	13%	11%	3%
Korea, Republic of	1,755	3%	13%	6%	52%	26%	0%
Latvia	85	6%	0%	0%	0%	13%	81%
Lebanon	182	8%	18%	8%	46%	19%	1%
Lithuania	154	0%	0%	0%	0%	0%	100%
Madagascar	73	4%	37%	16%	36%	7%	0%
Malawi	26	0%	38%	19%	42%	0%	0%
Malaysia	959	9%	22%	12%	44%	12%	1%
Maldives	15	7%	20%	20%	33%	20%	0%
Mali	136	14%	48%	19%	17%	1%	1%
Mauritania	70	10%	43%	16%	27%	4%	0%
Mauritius	82	2%	7%	11%	44%	30%	5%
Mexico	4,825	1%	11%	12%	49%	17%	10%
Mongolia	84	13%	39%	12%	31%	5%	0%
Montenegro	41	2%	15%	10%	32%	41%	0%
Morocco	595	11%	26%	13%	45%	5%	0%
Mozambique	104	7%	4%	10%	48%	2%	30%
Namibia	54	2%	11%	13%	44%	9%	20%
Nepal	585	7%	23%	13%	43%	9%	5%
Netherlands	1,310	5%	10%	7%	35%	43%	0%
New Zealand	270	1%	9%	10%	14%	24%	43%
Nicaragua	274	4%	15%	7%	54%	9%	11%
Nigeria	531	7%	36%	14%	24%	2%	17%
Norway	346	7%	15%	9%	36%	32%	0%
Pakistan	2,086	14%	32%	35%	16%	3%	0%
Palestine	292	4%	16%	8%	36%	13%	23%

	Hemophilia A	0–4	5–13	14–18	19–44	45+	Age not known
Panama	281	4%	16%	8%	51%	20%	0%
Paraguay	267	7%	21%	9%	51%	12%	0%
Philippines	1,187	4%	13%	12%	50%	8%	12%
Poland	2,605	0%	0%	0%	0%	0%	100%
Portugal	629	3%	7%	7%	32%	26%	25%
Qatar	51	12%	25%	27%	33%	2%	0%
Saudi Arabia	871	21%	38%	18%	22%	1%	0%
Senegal	261	11%	38%	15%	32%	4%	0%
Serbia	469	4%	13%	5%	48%	30%	0%
Singapore	224	7%	9%	6%	39%	38%	0%
Slovak Republic	546	3%	10%	7%	41%	39%	0%
Slovenia	224	0%	0%	0%	0%	0%	100%
South Africa	1,986	3%	14%	10%	42%	28%	2%
Sri Lanka	915	19%	17%	7%	22%	5%	30%
Sudan	1,072	22%	35%	14%	26%	3%	0%
Suriname	15	13%	20%	0%	47%	20%	0%
Syria	855	15%	27%	16%	35%	5%	2%
Tajikistan	519	7%	30%	11%	46%	5%	0%
Tanzania	126	6%	22%	13%	13%	1%	45%
Thailand	1,615	7%	26%	13%	45%	9%	0%
Togo	39	5%	36%	13%	36%	8%	3%
Uganda	261	34%	38%	9%	16%	3%	0%
United Kingdom	6,940	6%	12%	7%	39%	36%	0%
United States	11,790	8%	24%	12%	38%	18%	0%
Uruguay	238	3%	20%	10%	33%	24%	10%
Uzbekistan	1,559	8%	23%	9%	49%	10%	0%
Venezuela	2,266	5%	13%	9%	39%	17%	16%
Vietnam	3,228	6%	18%	11%	53%	12%	0%
Zambia	135	13%	33%	21%	13%	2%	17%
Zimbabwe	162	0%	6%	7%	69%	6%	12%

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

(98 countries reported age data for hemophilia B)

	Hemophilia B	0–4	5–13	14–18	19–44	45+	Age not known
Afghanistan	48	4%	40%	31%	25%	0%	0%
Albania	35	3%	6%	9%	63%	20%	0%
Algeria	126	12%	13%	10%	47%	18%	0%
Angola	10	10%	60%	10%	20%	0%	0%
Argentina	386	3%	15%	12%	48%	20%	3%
Armenia	24	25%	13%	4%	29%	29%	0%
Australia	539	5%	10%	9%	37%	39%	0%
Austria	149	5%	17%	11%	38%	30%	0%
Bahamas	2	50%	0%	0%	50%	0%	0%
Bangladesh	375	19%	34%	18%	26%	2%	0%
Barbados	11	9%	0%	18%	55%	18%	0%
Belgium	249	2%	9%	6%	35%	48%	0%
Belize	5	0%	0%	20%	80%	0%	0%
Bolivia	34	24%	26%	9%	41%	0%	0%
Botswana	8	13%	50%	0%	38%	0%	0%
Brazil	2,165	4%	14%	9%	50%	22%	0%
Burkina Faso	27	26%	37%	15%	22%	0%	0%
Cambodia	38	11%	37%	18%	24%	8%	3%
Cameroon	35	17%	49%	23%	11%	0%	0%
Canada	701	3%	11%	7%	40%	40%	0%
Chile	172	6%	14%	9%	52%	19%	0%
Colombia	686	4%	13%	8%	61%	13%	0%
Costa Rica	43	7%	19%	5%	56%	14%	0%
Cote d'Ivoire	17	18%	47%	18%	12%	6%	0%
Czech Republic	139	4%	14%	9%	21%	28%	24%
Dominican Republic	55	2%	7%	2%	53%	4%	33%
Egypt	1,149	5%	37%	13%	37%	7%	0%
El Salvador	23	26%	35%	17%	13%	9%	0%
Eritrea	7	14%	43%	0%	43%	0%	0%
Estonia	11	9%	27%	9%	27%	27%	0%
Ethiopia	33	6%	30%	15%	45%	3%	0%
France	1,674	7%	17%	11%	36%	29%	0%
Georgia	56	11%	20%	4%	39%	27%	0%
Ghana	27	33%	48%	19%	0%	0%	0%

	Hemophilia B	0–4	5–13	14–18	19–44	45+	Age not known
Greece	185	2%	9%	5%	30%	54%	0%
Guyana	1	0%	0%	0%	0%	100%	0%
Honduras	35	3%	29%	23%	43%	3%	0%
Hungary	239	3%	5%	4%	41%	47%	0%
India	3,104	2%	13%	11%	48%	12%	14%
Indonesia	353	9%	33%	22%	29%	2%	5%
Iran	1,147	3%	12%	8%	57%	20%	0%
Iraq	518	22%	40%	20%	13%	5%	0%
Ireland	228	4%	14%	13%	38%	32%	0%
Israel	107	14%	14%	16%	37%	19%	0%
Italy	887	3%	12%	13%	36%	37%	0%
Jamaica	5	0%	20%	0%	40%	40%	0%
Kenya	142	25%	25%	30%	17%	3%	1%
Korea, Republic of	438	1%	16%	10%	48%	24%	0%
Latvia	16	0%	0%	0%	0%	6%	94%
Lebanon	49	2%	20%	10%	57%	10%	0%
Lithuania	27	0%	0%	0%	0%	0%	100%
Madagascar	63	11%	46%	16%	25%	2%	0%
Malawi	5	0%	40%	40%	20%	0%	0%
Malaysia	180	11%	18%	12%	47%	13%	0%
Maldives	4	0%	75%	0%	25%	0%	0%
Mali	14	43%	36%	7%	14%	0%	0%
Mauritania	18	17%	44%	11%	22%	6%	0%
Mauritius	9	0%	22%	11%	67%	0%	0%
Mexico	722	2%	12%	12%	50%	16%	7%
Montenegro	4	0%	0%	0%	75%	25%	0%
Morocco	137	13%	22%	12%	50%	3%	0%
Nepal	109	3%	19%	23%	37%	14%	5%
Netherlands	188	4%	10%	10%	35%	41%	0%
New Zealand	48	2%	6%	2%	13%	17%	60%
Nicaragua	28	0%	14%	7%	18%	7%	54%
Nigeria	24	21%	38%	21%	8%	0%	13%
Norway	94	4%	17%	10%	36%	33%	0%
Pakistan	373	9%	26%	17%	42%	6%	0%
Palestine	60	5%	20%	3%	38%	15%	18%
Panama	37	8%	14%	14%	49%	16%	0%
Paraguay	29	3%	34%	10%	34%	17%	0%

	Hemophilia B	0–4	5–13	14–18	19–44	45+	Age not known
Philippines	207	5%	15%	10%	54%	6%	9%
Poland	484	0%	0%	0%	0%	0%	100%
Portugal	148	5%	7%	9%	34%	33%	13%
Qatar	9	33%	11%	22%	33%	0%	0%
Saudi Arabia	195	20%	38%	13%	29%	1%	0%
Senegal	37	22%	49%	19%	11%	0%	0%
Serbia	88	2%	18%	7%	49%	24%	0%
Singapore	46	0%	20%	9%	50%	22%	0%
Slovak Republic	84	7%	13%	13%	44%	23%	0%
Slovenia	30	0%	0%	0%	0%	0%	100%
South Africa	379	2%	18%	10%	42%	27%	1%
Sri Lanka	221	21%	19%	8%	5%	9%	39%
Sudan	259	19%	41%	17%	22%	2%	0%
Syria	98	12%	28%	19%	37%	2%	2%
Tajikistan	41	10%	27%	17%	37%	10%	0%
Tanzania	20	10%	30%	10%	15%	0%	35%
Thailand	213	6%	31%	13%	38%	13%	0%
Togo	7	0%	29%	43%	0%	14%	14%
Uganda	40	28%	38%	15%	20%	0%	0%
United Kingdom	1,569	5%	15%	6%	38%	36%	0%
United States	3,026	10%	20%	11%	34%	25%	0%
Uruguay	39	5%	23%	10%	49%	10%	3%
Uzbekistan	177	16%	21%	10%	47%	6%	0%
Venezuela	602	3%	13%	7%	40%	20%	16%
Vietnam	685	6%	20%	10%	51%	13%	0%
Zambia	27	30%	7%	48%	15%	0%	0%
Zimbabwe	11	0%	18%	9%	45%	18%	9%

TABLE 12. **Age distribution: Hemophilia Type Unknown**

(27 countries reported age data)

	Hemophilia type unknown	0–4	5–13	14–18	19–44	45+	Age not known
Bahamas	1	0%	100%	0%	0%	0%	0%
Bangladesh	6	0%	0%	100%	0%	0%	0%
Belgium	8	0%	0%	0%	13%	88%	0%
Chile	55	0%	0%	2%	65%	33%	0%
Cote d'Ivoire	1	0%	0%	0%	0%	100%	0%
Dominican Republic	31	0%	23%	3%	45%	10%	19%
Ethiopia	159	4%	45%	17%	34%	0%	0%
Ghana	45	42%	20%	18%	20%	0%	0%
Honduras	25	0%	24%	12%	20%	4%	40%
India	562	0%	2%	4%	30%	6%	57%
Indonesia	110	5%	31%	8%	40%	5%	12%
Iran	3,790	5%	19%	10%	51%	15%	0%
Jamaica	3	0%	0%	0%	0%	0%	100%
Lithuania	1	0%	0%	0%	0%	0%	100%
Malawi	52	23%	35%	12%	21%	0%	10%
Mali	12	0%	67%	0%	17%	0%	17%
Mexico	305	1%	3%	6%	26%	15%	49%
Nicaragua	120	13%	27%	8%	32%	8%	14%
Nigeria	75	8%	49%	13%	20%	1%	8%
Philippines	210	1%	9%	12%	46%	6%	26%
Syria	4	50%	25%	25%	0%	0%	0%
Tanzania	19	16%	21%	21%	26%	0%	16%
Togo	4	0%	50%	25%	25%	0%	0%
Uganda	2	0%	50%	0%	50%	0%	0%
Uruguay	16	6%	6%	0%	6%	0%	81%
Uzbekistan	10	0%	0%	100%	0%	0%	0%
Zambia	36	19%	0%	56%	0%	0%	25%

TABLE 13. **Age distribution: VWD**

(84 countries reported age data)

	Total number of patients	0–4	5–13	14–18	19–44	45+	Age not known
Afghanistan	2	0%	0%	100%	0%	0%	0%
Albania	7	0%	14%	14%	57%	14%	0%
Argentina	397	0%	0%	2%	42%	41%	14%
Australia	2,324	1%	9%	7%	44%	40%	0%
Bahamas	2	0%	0%	0%	100%	0%	0%
Bangladesh	5	20%	40%	0%	40%	0%	0%
Belgium	2,202	1%	9%	10%	44%	35%	1%
Bolivia	3	0%	67%	0%	0%	33%	0%
Botswana	7	0%	43%	57%	0%	0%	0%
Brazil	9,768	1%	9%	8%	54%	28%	0%
Cambodia	7	0%	57%	43%	0%	0%	0%
Cameroon	5	0%	0%	0%	60%	40%	0%
Canada	4,709	1%	7%	7%	48%	37%	0%
Colombia	3,446	4%	12%	17%	54%	12%	1%
Costa Rica	93	0%	1%	8%	48%	43%	0%
Cote d'Ivoire	3	0%	33%	0%	33%	33%	0%
Cuba	473	1%	12%	27%	40%	20%	0%
Czech Republic	779	1%	7%	7%	35%	31%	19%
Djibouti	2	0%	0%	0%	100%	0%	0%
Dominican Republic	52	4%	6%	8%	48%	8%	27%
Egypt	647	5%	43%	11%	32%	9%	0%
El Salvador	2	0%	50%	0%	50%	0%	0%
Estonia	128	3%	21%	9%	45%	15%	7%
France	2,992	4%	14%	11%	38%	33%	0%
Georgia	55	4%	20%	13%	42%	22%	0%
Ghana	11	27%	36%	0%	36%	0%	0%
Honduras	21	0%	29%	14%	38%	10%	10%
Hungary	1,418	1%	7%	6%	36%	50%	0%
India	743	2%	17%	13%	46%	10%	12%
Indonesia	20	5%	25%	15%	40%	10%	5%
Iran	1,755	3%	16%	12%	53%	16%	0%
Iraq	671	16%	34%	31%	16%	3%	0%

	Total number of patients	0–4	5–13	14–18	19–44	45+	Age not known
Ireland	1,762	5%	19%	8%	42%	26%	0%
Italy	3,245	0%	0%	0%	0%	0%	100%
Jamaica	3	0%	0%	0%	0%	100%	0%
Kenya	37	14%	41%	30%	14%	3%	0%
Korea, Republic of	152	2%	11%	9%	53%	24%	0%
Latvia	71	4%	0%	0%	0%	3%	93%
Lebanon	178	4%	20%	6%	52%	13%	4%
Lithuania	305	0%	0%	0%	0%	0%	100%
Madagascar	2	0%	50%	0%	0%	50%	0%
Mali	23	17%	26%	13%	39%	4%	0%
Mauritania	1	0%	100%	0%	0%	0%	0%
Mauritius	1	0%	100%	0%	0%	0%	0%
Mexico	355	0%	10%	10%	43%	15%	21%
Mongolia	14	0%	14%	29%	43%	14%	0%
Montenegro	3	0%	0%	0%	100%	0%	0%
Morocco	173	17%	14%	50%	19%	0%	0%
Nepal	9	11%	33%	22%	11%	11%	11%
Netherlands	460	2%	17%	9%	30%	43%	0%
New Zealand	90	0%	0%	0%	0%	0%	100%
Nicaragua	60	3%	20%	13%	23%	8%	32%
Nigeria	13	0%	23%	8%	46%	0%	23%
Norway	601	3%	7%	8%	36%	46%	0%
Pakistan	389	8%	35%	36%	18%	3%	0%
Palestine	59	2%	20%	12%	47%	2%	17%
Panama	521	0%	11%	17%	56%	15%	0%
Paraguay	4	0%	25%	0%	75%	0%	0%
Philippines	46	0%	4%	11%	30%	7%	48%
Poland	2,250	0%	0%	0%	0%	0%	100%
Portugal	479	1%	4%	4%	21%	25%	46%
Qatar	45	7%	27%	33%	33%	0%	0%
Saudi Arabia	396	18%	38%	22%	20%	2%	0%
Senegal	13	15%	31%	38%	8%	8%	0%
Serbia	317	1%	9%	4%	50%	37%	0%
Singapore	93	1%	12%	4%	35%	47%	0%
Slovak Republic	765	0%	6%	6%	53%	34%	0%

	Total number of patients	0–4	5–13	14–18	19–44	45+	Age not known
Slovenia	189	0%	0%	0%	0%	0%	100%
South Africa	659	0%	4%	6%	42%	44%	4%
Sri Lanka	67	13%	27%	4%	10%	12%	33%
Sudan	367	21%	35%	16%	24%	4%	0%
Suriname	3	0%	0%	33%	33%	33%	0%
Syria	133	14%	28%	14%	38%	6%	0%
Tajikistan	35	6%	20%	23%	46%	6%	0%
Tanzania	5	0%	0%	20%	0%	0%	80%
Thailand	150	2%	10%	9%	55%	24%	0%
Uganda	3	0%	0%	67%	33%	0%	0%
United Kingdom	11,183	2%	10%	6%	40%	40%	0%
United States	8,919	5%	29%	22%	29%	15%	0%
Uzbekistan	177	7%	27%	14%	46%	7%	0%
Venezuela	1,184	1%	13%	11%	39%	17%	18%
Vietnam	184	4%	28%	15%	40%	13%	0%
Zambia	5	0%	0%	80%	0%	20%	0%
Zimbabwe	1	0%	0%	0%	100%	0%	0%

TABLE 14. **HIV and HCV infection**

(84 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
Afghanistan				6					
Albania	1	0	0	32	0	0	6	0	0
Algeria	1			19	3	2	2	0	0
Argentina	54	0	0	600	20	0			
Armenia		1		62			2		
Austria	44			192					
Bahamas	0	0	0	0	0	0	0	0	0
Barbados	0			1			0		
Belarus	0	0	0		0	0		0	0
Botswana	3	0	0						
Burkina Faso	0	0	0						
Cambodia				0	0		0	0	
Cameroon	0	0	0	0	0	0	0	0	0
Chile	5								
Colombia	10	2	0	192	50	0	81	10	0
Costa Rica	11	0	0	21	0	0	0	0	0
Cote d'Ivoire	1	0	0	0	0	0	0	0	0
Cuba	3	0	0	133	16	2	125	16	2
Czech Republic	3	0	0	187	5	1	57	1	0
Djibouti	0								
Dominican Republic				28	0	8	20	0	8
Ecuador	10	10		18	3		16	3	
El Salvador	0	0	0	0	0	0	0	0	0
Estonia	1	0	0	28	1				
France	543	20	5	2,123	192	53	39	6	0
Georgia				11					
Germany	343								

	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	47	2	0	281	20	10	10	1	0
Guyana	0			0					
Honduras	0	1	0						
Hungary	10			371	111				
India	29	2	0	84	3				
Indonesia	2								
Iran	24	1	1	1,069	155	152	70	10	10
Iraq	0	0	0	305	66				
Ireland	31	0	0	139	7	2	3	0	0
Israel	23								
Italy	222	9	0	1,142	108	0			
Jamaica	1	0	0	2	0	0	1	0	0
Japan	700	7	3	1,542	105	64	872	1	41
Jordan	2			46					
Korea, Republic of	17	0	0	451	2	4	71	0	0
Lebanon	0	0	0	0	0	0	0	0	0
Lithuania	0	0	0						
Madagascar	0	0	0	0	0	0	0	0	0
Malaysia	10	0	0	93	0	0	54	0	0
Mali	0	0	0	0	0	0	0	0	0
Mauritius	0	0	0	8		1			
Mexico	43	3	0	266	6	0			
Montenegro	0	0	0	3	0	0	0	0	0
Morocco	0	0	0	85	1	0	2	0	0
Mozambique	5			2					
Nepal	0			9					
New Zealand	3			1			1		
Norway	6	0		104					
Pakistan	14	0	3	228	58	295	228	58	295
Palestine	0	0	0						
Panama	0	0	0	0	0	0	0	0	0
Qatar	0	0	0	0	0	0	0	0	0
Saudi Arabia	0			1			1		

	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
Senegal	0	0	0	0	1	0	0	1	0
Serbia	7	2	0	115	5	2			
Singapore	0	0	0	69	2	0	0	0	0
Slovak Republic	0	0	0	120	12	12	14	1	0
Slovenia	7	0	0	96	6	0	0	0	0
South Africa	80	3	0	280	2	0			
Sri Lanka	0	0	0						
Sudan	2	1	1	43					
Suriname	0	0	0	0	0	0	0	0	0
Sweden	29	0	0						
Switzerland	11	0	0	117	11	1			
Syria				71	6				
Tajikistan				32	22		10	5	
Thailand	21	0	0	64	0	0	0	0	0
Tunisia	10			51					
Uganda	1	1							
United Kingdom	258	4	1	1,547	170	30	66	10	2
United States	719	9	5				1,300		
Uruguay	0	0	0	6	0	0	6	0	0
Uzbekistan	8	0		193	10				
Venezuela	18	4	1	318	24	0	258	18	0
Vietnam	5	0	0	353	2	46	0	0	0
Zambia	1	0	0	0	0	0	0	0	0

** Hepatitis C antibody positive at any time*

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

TABLE 15. **Percentage of patients on prophylaxis**

(95 countries reported prophylaxis data)

	Percent under 18 on prophylaxis	Precise or estimate	Percent over 18 on prophylaxis	Precise or estimate
Afghanistan	2	Estimate		
Algeria	90	Estimate	35	Estimate
Argentina	80	Estimate	15	Estimate
Armenia	50	Estimate	25	Estimate
Australia	92	Estimate	76	Estimate
Austria	88	Precise	74	Precise
Bahamas	0	Precise	0	Precise
Barbados	6	Estimate	1	Estimate
Belarus	100	Estimate	2	Estimate
Belgium	90	Estimate	75	Estimate
Bolivia	50	Estimate		
Bosnia-Herzegovina	90	Estimate		
Botswana	100	Precise	80	Estimate
Brazil	87	Precise	64	Precise
Cambodia	2	Estimate	1	Estimate
Cameroon	0	Precise	0	Precise
Canada	91	Estimate	82	Estimate
Chile	100	Estimate	50	Estimate
Colombia	97	Precise	85	Precise
Costa Rica	50	Precise	50	Precise
Cote d'Ivoire	34	Precise	0	Precise
Cuba	12	Precise		
Czech Republic	87	Precise	68	Precise
Dominican Republic	35	Precise	0	Precise
Egypt	5	Estimate	1	Estimate
Eritrea	90	Estimate	0	Precise
Estonia	88	Precise	20	Precise
Ethiopia	0	Precise	0	Precise
Finland	80	Estimate		
France	80	Precise	62	Precise
Georgia	30	Estimate		
Germany	100	Estimate		
Ghana	60	Estimate	50	Estimate
Greece	93	Precise	67	Precise

	Percent under 18 on prophylaxis	Precise or estimate	Percent over 18 on prophylaxis	Precise or estimate
Guatemala	17	Precise	1	Precise
Guyana	80	Precise	100	Precise
Hungary	100	Precise	70	Estimate
India	9	Precise	4	Estimate
Indonesia	0	Precise	0	Precise
Iran	45	Precise	25	Precise
Iraq	100	Precise	10	Precise
Ireland	96	Estimate	95	Estimate
Israel	95	Precise	72	Precise
Jamaica	0	Precise	0	Precise
Japan	10	Estimate	14	Estimate
Jordan	10	Estimate	10	Estimate
Kenya	0	Precise	0	Precise
Korea, Republic of	75	Precise	60	Precise
Kuwait	90	Estimate		
Latvia			100	Precise
Lebanon	32	Estimate	15	Estimate
Lesotho	0	Estimate	0	Estimate
Lithuania	100	Precise	60	Precise
Madagascar	10	Estimate	10	Estimate
Malawi	29	Estimate	24	Estimate
Malaysia	85	Estimate	80	Estimate
Maldives	1	Estimate		
Mali	95	Estimate	10	Estimate
Mauritius	100	Precise	100	Precise
Montenegro	89	Precise	67	Precise
Morocco	25	Estimate	10	Estimate
Mozambique	20	Estimate	30	Estimate
Netherlands			90	Estimate
New Zealand	97	Estimate	71	Estimate
Nicaragua	0	Precise	0	Precise
Nigeria	98	Estimate	0	Precise
Norway	95	Estimate	80	Estimate
Pakistan	60	Precise	0	Precise
Palestine	65	Estimate	25	Estimate
Panama	100	Estimate		
Philippines	1	Estimate	0	Estimate
Poland	80	Estimate	60	Estimate

	Percent under 18 on prophylaxis	Precise or estimate	Percent over 18 on prophylaxis	Precise or estimate
Qatar	80	Precise	80	Precise
Romania	100	Precise	40	Precise
Russia	90	Estimate	65	Estimate
Saudi Arabia	30	Estimate	50	Estimate
Senegal	19	Precise	0	Precise
Serbia	90	Precise	35	Precise
Singapore	92	Precise	58	Precise
Slovak Republic	96	Precise	63	Precise
Slovenia	100	Precise	78	Precise
South Africa	40	Estimate	25	Estimate
Suriname	20	Precise	0	Precise
Sweden	95	Estimate	90	Estimate
Thailand	30	Estimate	10	Estimate
Togo	0	Estimate	0	Estimate
Tunisia	78	Precise	53	Precise
Uganda	1	Precise	1	Precise
Ukraine*	100	Precise	50	Estimate
United Kingdom	92	Estimate	87	Estimate
Uruguay	100	Estimate	10	Estimate
Uzbekistan	5	Precise	0	Precise
Venezuela	35	Precise	10	Precise
Vietnam	11	Estimate	1	Estimate
Zambia	29	Precise	29	Precise

** Data updated after publication. These updates are not reflected in any other calculations or summary tables in this report.*

TABLE 16. **Use of Factor Concentrates in 2020: Factor VIII**

(105 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 2020 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	1,000,000							1,000,000	1,000,000	0	0.026	
Albania	7,600,000	3,000,000	100,000		97	3		4,500,000			2.678	1.092
Algeria	100,115,000	64,050,000	36,065,000		64	36					2.283	2.283
Angola	588,000	0	0	138,000	0	0	100	450,000	450,000	0	0.018	0.004
Argentina	195,300,000	116,900,000	74,200,000	4,000,000	60	38	2	200,000	200,000	0	4.304	4.3
Armenia	2,800,000							1,400,000	900,000	500,000	0.945	0.472
Australia	192,058,140	21,985,500	136,063,890	34,008,750	11	71	18	0			7.477	7.477
Bahamas	299,324	0	0	13,500	0	0	100	285,824	200,000	0	0.761	0.034
Bangladesh	6,565,000	1,500,000			100			5,065,000	3,736,500	1,328,500	0.04	0.009
Barbados	375,000							375,000	375,000	0	1.305	
Belarus	42,000,000	40,000,000	0	0	100	0	0	2,000,000			4.469	4.256
Belize	390,802							390,802	350,000	0	0.983	0
Bolivia	1,500,000							1,500,000	600,000	0	0.129	
Brazil	905,508,250	214,283,750	691,224,500	0	24	76	0	0			4.26	4.26
Burkina Faso	464,500							464,500	300,000	50,000	0.022	0
Cambodia	1,727,500							1,727,500	1,177,500	550,000	0.103	
Cameroon	900,000							900,000	700,000	200,000	0.034	
Canada	293,465,240	32,979,566	177,886,337	82,599,337	11	61	28	0			7.722	7.722
Chile	78,000,000	78,000,000			100			0			4.08	4.08
Colombia	286,293,000	62,931,000	209,479,000	13,883,000	22	73	5	0			5.627	5.627
Costa Rica	15,787,020	15,787,020	0	0	100	0	0	0			3.099	3.099

	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
Cote d'Ivoire	1,457,000							1,457,000			0.055	0
Cuba	5,935,000	5,225,000	0	0	100	0	0	710,000	710,000	0	0.524	0.461
Czech Republic	53,480,580	6,948,500	28,782,830	17,749,250	13	54	33	0			4.999	4.999
Djibouti	600	40	0	0	7	0	0				0.001	0.001
Dominican Republic	1,900,000							1,900,000	1,200,000	700,000	0.175	
Ecuador	41,117,250	34,943,250		6,174,000	85		15				2.331	2.331
Egypt	100,654,500	76,054,500	11,500,000	0	87	13	0	13,100,000	7,400,000	5,700,000	0.984	0.856
El Salvador	1,700,000							1,700,000	800,000	900,000	0.262	
Eritrea	533,000							533,000	428,000	0	0.15	0
Estonia	6,809,750	302,500	454,000	6,053,250	4	7	89	0			5.116	5.116
Ethiopia	1,750,500							1,750,500	1,300,500	450,000	0.015	0
Finland	42,412,750	2,811,000	16,718,500	22,883,250	7	39	54				7.669	7.669
France	453,274,750	35,449,000	208,969,500	208,856,250	8	46	46				6.726	6.726
Georgia	14,500,000	14,500,000			100						3.904	3.904
Germany	651,042,701	181,385,330	469,657,371		28	72		0			7.821	7.821
Ghana	1,750,000							1,750,000	1,000,000	750,000	0.056	0
Greece	55,772,550	2,543,000	33,826,050	19,403,500	5	61	35	0			5.205	5.205
Guyana	750,000							750,000	750,000	0	0.954	
Honduras	3,270,500	2,470,500			100			800,000	500,000	300,000	0.33	0.249
Hungary	126,700,000	51,000,000	75,700,000		40	60					12.995	12.995
India	374,122,500	140,000,000	205,000,000		41	59		29,122,500	20,822,500	8,300,000	0.271	0.25
Indonesia	55,012,475	50,906,475	0	0	100	0	0	4,106,000	735,000	1,150,000	0.201	0.186
Iran	89,054,250	47,723,250	41,331,000		54	46					1.06	1.06
Iraq	32,000,000	0	32,000,000	0	0	100	0	0			0.796	0.796
Ireland	39,825,750	0	159,250	39,666,500	0	0	100	0			7.974	7.974
Italy	492,000,000	53,400,000			11						8.261	8.261
Jamaica	700,000							700,000	430,000	50,000	0.236	0
Japan	665,819,000	48,261,000	220,581,000	396,977,000	7	33	60	0			5.291	5.291
Jordan	7,984,500							484,500	211,500	273,000	0.783	0.735
Kenya	5,611,250							5,611,250	2,000,000	1,250,000	0.104	0
Korea, Republic of	296,247,000	55,844,000	240,403,000		19	81					5.721	5.721
Latvia	9,592,750	952,500	7,746,250	894,000	10	81	9	0			5.045	5.045

	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
Lebanon	13,440,000			0			0	1,990,000	1,990,000	0	1.969	1.678
Lithuania	31,776,000	10,979,000	20,466,000	331,000	35	64	1				11.37	11.37
Madagascar	1,356,500							1,356,500	757,500	599,000	0.049	
Malawi	684,514							684,514	400,000	50,000	0.036	
Maldives	230,000							230,000	230,000	0	0.425	
Mali	2,150,000							2,150,000	1,500,000	650,000	0.106	
Mauritania	373,000	99,500	0	0	100	0	0	273,500	100,000	100,000	0.08	0.021
Mauritius	6,140,000	5,625,000	0	0	100	0	0	515,000	515,000	0	4.851	4.444
Mexico	249,263,690	41,595,250	198,820,250	0	17	83	0	8,848,190			1.933	1.865
Mongolia	3,030,500							1,294,000	550,000	500,000	0.924	0.53
Montenegro	1,650,000	1,650,000	0	0	100	0	0	0			2.654	2.654
Morocco	27,817,311	14,376,561	12,390,750	0	54	46	0	1,050,000	0	1,050,000	0.754	0.725
Mozambique	450,000							450,000	450,000	0	0.014	
Nepal	3,841,394							3,841,394	1,816,000	1,107,750	0.132	
Nicaragua	1,606,044							1,606,044	550,000	602,250	0.242	0
Nigeria	3,956,500							3,956,500	2,345,500	1,611,000	0.019	
Pakistan	8,649,750	418,000	0	0	100	0	0	8,231,750	1,500,000	3,625,000	0.039	0.002
Palestine	5,264,500							700,000	700,000	0	1.096	0.95
Panama	13,070,000										3.029	3.029
Paraguay	800,000							800,000	650,000	150,000	0.112	
Peru	578,000							578,000			0.018	
Philippines	1,950,250	1,365,000		0	100		0	585,250	150,000	0	0.018	0.012
Poland	323,710,825	297,500,700	26,210,125		92	8					8.53	8.53
Portugal	58,033,000	11,500,000	27,218,750	19,314,250	20	47	33				5.631	5.631
Qatar	18,500,000	0	14,500,000	4,000,000		78	22				6.421	6.421
Romania	65,822,650	4,642,710	2,687,000		7	4		0			3.413	3.413
Russia	881,760,000	526,548,000	355,212,000		60	40					6.119	6.119
Saudi Arabia	148,120,000	57,960,000	66,160,000	24,000,000	39	45	16	0			4.255	4.255
Senegal	1,355,500	3,500	0	0	100	0	0	1,352,000	700,000	200,000	0.081	0
Serbia	29,575,000	8,575,000	21,000,000	0	29	71	0	0			4.281	4.281
Singapore	13,344,750	2,117,750	11,227,000	0	16	84	0	0			2.347	2.347
Slovak Republic	48,867,000	30,960,000	12,207,000	5,700,000	63	25	12	0			8.952	8.952
South Africa	73,213,600	71,309,100	1,904,500	0	97	3	0	0			1.234	1.234

	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
Sri Lanka	15,594,000	12,966,000			100			2,628,000	1,000,000	1,628,000	0.711	0.592
Sudan	11,525,000										0.263	0.263
Sweden	100,406,750	0	55,945,250	44,461,500		56	44	0			9.698	9.698
Syria	12,174,000	11,825,000	0	0	100	0	0	349,000			0.696	0.676
Tajikistan	300,750							750	300,000	0	0.032	0.031
Tanzania	800,000							800,000	650,000	150,000	0.013	0
Thailand	43,977,000	28,157,500	14,319,500	0	66	34	0	1,500,000	1,000,000	500,000	0.63	0.609
Togo	350,000							350,000	350,000	0	0.042	
Tunisia	18,028,250	10,446,000	7,582,250	0	58	42	0	0			1.525	1.525
Uganda	2,325,000							2,325,000	1,800,000	525,000	0.051	
Ukraine*	132,451,500	60,188,750	72,262,750	0	45	55	0	300,000			3.008	3.001
United Kingdom	488,434,104	4,600,020	390,949,758	92,884,326	1	80	19				7.267	7.267
United States	2,150,000,000	153,000,000	1,436,000,000	561,000,000	7	67	26				6.525	6.525
Uruguay	9,100,000		0	0		0	0	0			2.62	2.62
Uzbekistan	8,080,500	1,752,250	0	0	100	0	0	6,328,250	4,825,000	950,000	0.236	0.051
Venezuela	8,938,000							8,938,000	3,100,000	3,200,000	0.314	0
Vietnam	26,896,050	25,276,300	127,250	0	99	1	0	1,492,500	0	700,000	0.276	0.261
Zambia	1,024,500							1,024,500	700,500	224,000	0.056	
Zimbabwe	627,000							627,000	527,000	100,000	0.042	
TOTAL	**10,836,930,364**	**2,857,573,572**	**5,665,037,611**	**1,604,990,663**				**151,889,018**	**77,433,000**	**40,673,500**		

** Data updated after publication. These updates are not reflected in any other calculations or summary tables in this report.*

TABLE 17. **Use of Factor Concentrates in 2020: Factor IX**

(98 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 2020 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	100,000							100,000	1,000,000	0	0.00257	
Albania	618,000	100,000	50,000		67	33		468,000			0.21778	0.05286
Algeria	16,440,000										0.37491	0.37491
Angola	17,500	0	0	17,500	0	0	100		450,000	0	0.00053	0.00053
Argentina	24,500,000	16,700,000	7,800,000	0	68	32	0	0	200,000	0	0.53992	0.53992
Armenia	386,000							186,000	900,000	500,000	0.13026	0.06749
Australia	26,725,250	549,000	14,457,500	11,718,750	2	54	44	0			1.04042	1.04042
Bangladesh	1,047,500							1,047,500	3,736,500	1,328,500	0.00636	
Barbados	21,000							21,000	375,000	0	0.07308	
Belize	28,500							28,500	350,000	0	0.07168	
Brazil	142,228,200	142,228,200	0	0	100	0	0	0			0.66912	0.66912
Burkina Faso	240,500							240,500	300,000	50,000	0.01151	0
Cambodia	300,000							300,000	1,177,500	550,000	0.01794	
Cameroon	100,000							100,000	700,000	200,000	0.00377	
Canada	50,345,309	3,455,584	31,637,559	15,252,166	7	63	30	0			1.32469	1.32469
Chile	14,000,000	14,000,000			100						0.73236	0.73236
Colombia	39,010,000	18,307,000	17,111,000	3,592,000	47	44	9	0			0.76666	0.76666
Costa Rica	3,261,000	3,261,000	0	0	100	0	0	0			0.64015	0.64015
Cote d'Ivoire	456,250							456,250			0.0173	0
Cuba	350,000	350,000	0	0	100	0	0	0	710,000	0	0.0309	0.0309
Czech Republic	7,078,449	1,645,052	3,658,257	1,775,140	23	52	25	0			0.66161	0.66161
Dominican Republic	350,000							350,000	1,200,000	700,000	0.03226	

	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
Ecuador	2,140,000	2,140,000			100						0.12129	0.12129
Egypt	2,562,500			0				2,562,500	7,400,000	5,700,000	0.02504	
El Salvador	180,000							180,000	800,000	900,000	0.02775	
Eritrea	12,000							12,000	428,000	0	0.00338	0
Estonia	726,800	726,800	0	0	100	0	0	0			0.54603	0.54603
Ethiopia	352,750							352,750	1,300,500	450,000	0.00307	0
Finland	8,423,000	628,000	6,208,500	1,586,500	7	74	19				1.52295	1.52295
France	78,365,250	5,224,500	15,697,750	57,443,000	7	20	73				1.16283	1.16283
Georgia	1,400,000	1,400,000			100						0.37695	0.37695
Germany	65,959,350	16,074,900	49,884,450		24	76		0			0.79239	0.79239
Ghana	413,000							413,000	1,000,000	750,000	0.01329	0
Greece	6,799,750	0	3,157,500	3,642,250	0	46	54	0			0.63457	0.63457
Honduras	105,000							105,000	500,000	300,000	0.0106	
Hungary	10,100,000	10,100,000	0		100	0					1.03592	1.03592
India	16,118,000	14,675,000	225,000		98	2		1,218,000	20,822,500	8,300,000	0.01168	0.0108
Indonesia	5,330,000	5,020,000	0	0	100	0	0	310,000	735,000	1,150,000	0.01949	0.01835
Iran	11,435,000	11,435,000			100						0.13614	0.13614
Iraq	10,000,000	0	10,000,000	0	0	100	0	0			0.24862	0.24862
Ireland	9,425,000	0	0	9,425,000	0	0	100	0			1.88699	1.88699
Italy	394,000,000	6,600,000		18,690,000	2		5				6.61584	6.61584
Jamaica	137,500							137,500	430,000	50,000	0.04643	0
Japan	106,863,000	15,020,000	20,804,000	71,039,000	14	19	66	0			0.84922	0.84922
Jordan	2,371,000							171,000	211,500	273,000	0.23238	0.21562
Kenya	600,000							600,000	2,000,000	1,250,000	0.01116	0
Korea, Republic of	71,619,000	3,183,000	68,436,000		4	96					1.38312	1.38312
Latvia	717,000	717,000	0	0	100	0	0	0			0.37706	0.37706
Lebanon	3,396,500			0			0	196,500	1,990,000	0	0.49762	0.46883
Lithuania	10,774,500	10,774,500	0	0	100	0	0				3.85533	3.85533
Madagascar	1,050,000							1,050,000	757,500	599,000	0.03792	
Malawi	47,000							47,000	400,000	50,000	0.00246	
Maldives	500,100							500,100	230,000	0	0.92518	
Mali	182,000							182,000	1,500,000	650,000	0.00899	
Mauritania	68,500	42,500	0	0	100	0	0	26,000	100,000	100,000	0.01473	0.00914

	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
Mauritius	355,000	350,000	0	0	100	0	0	5,000	515,000	0	0.28047	0.27652
Mexico	4,000			0				4,000			0.00003	
Mongolia	873,750							150,000	550,000	500,000	0.26653	0.22077
Montenegro	275,000	275,000	0	0	100	0	0	0			0.44232	0.44232
Morocco	3,495,620	2,125,370	1,332,750	0	61	39	0	37,500	0	1,050,000	0.09471	0.09369
Nepal	375,000							375,000	1,816,000	1,107,750	0.01287	
Nicaragua	573,500							573,500	550,000	602,250	0.08657	0
Nigeria	250,000							250,000	2,345,500	1,611,000	0.00121	
Pakistan	1,571,250	162,500	0	0	100	0	0	1,408,750	1,500,000	3,625,000	0.00711	0.00074
Palestine	509,500							0	700,000	0	0.10607	0.10607
Panama	1,558,350	1,452,600	105,750	0	93	7	0				0.36117	0.36117
Paraguay	417,000							417,000	650,000	150,000	0.05846	
Peru	150,000							150,000			0.00455	
Philippines	93,500							93,500	150,000	0	0.00085	0
Poland	44,746,750	40,295,000	4,451,750		90	10					1.17907	1.17907
Portugal	8,877,250	3,600,000	3,517,250	1,760,000	41	40	20				0.8614	0.8614
Qatar	5,500,000	3,500,000		0	64		0				1.90902	1.90902
Romania	7,475,050							0			0.38759	0.38759
Russia	136,578,000	101,818,000	34,760,000		75	25					0.94777	0.94777
Saudi Arabia	19,800,000	11,555,000	6,600,000	1,650,000	58	33	8	0			0.56874	0.56874
Senegal	435,000							435,000	700,000	200,000	0.02598	0
Serbia	3,700,000	1,100,000	2,600,000	0	30	70	0	0			0.53559	0.53559
Singapore	3,434,000	228,000	3,087,000	119,000	7	90	3	0			0.60396	0.60396
Slovak Republic	4,800,000	3,000,000	200,000	1,600,000	63	4	33	0			0.87931	0.87931
South Africa	10,774,500	10,774,500	0	0	100	0	0	0			0.18167	0.18167
Sri Lanka	3,007,100	2,964,600			100			42,500	1,000,000	1,628,000	0.13719	0.13525
Sudan	1,685,000										0.03843	0.03843
Sweden	16,798,400	2,253,400	5,427,500	9,117,500	13	32	54	0			1.62249	1.62249
Syria	1,655,000	1,655,000	0	0	100	0	0	0			0.09457	0.09457
Tanzania	105,000							105,000	650,000	150,000	0.00176	0
Thailand	4,276,308	4,276,308	0	0	100	0	0		1,000,000	500,000	0.06127	0.06127
Togo	50,000							50,000	350,000	0	0.00604	
Tunisia	2,760,750	2,760,750	0	0	100	0	0	0			0.23359	0.23359

	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
Uganda	398,000							398,000	1,800,000	525,000	0.0087	
Ukraine*	21,235,700	10,502,100	10,733,600	0	49	51	0				0.48116	0.48116
United Kingdom	72,305,682	2,150,165	32,887,517	37,268,000	3	45	52				1.07573	1.07573
United States	622,000,000	45,000,000	257,000,000	320,000,000	7	41	51				1.8878	1.8878
Uruguay	600,000		0	0		0	0	0			0.17273	0.17273
Uzbekistan	2,969,000	1,334,500	0	0	100	0	0	1,634,500	4,825,000	950,000	0.08673	0.03898
Venezuela	1,200,000							1,200,000	3,100,000	3,200,000	0.0422	0
Vietnam	4,823,400	4,423,400	0	0	100	0	0	400,000	0	700,000	0.04955	0.04544
Zambia	268,250							268,250	700,500	224,000	0.01459	
Zimbabwe	50,000							50,000	527,000	100,000	0.00336	
TOTAL	**2,162,586,568**	**561,913,229**	**611,830,633**	**565,695,806**				**19,408,600**	**75,133,000**	**40,673,500**		

** Data updated after publication. These updates are not reflected in any other calculations or summary tables in this report.*

TABLE 18. **Use of Hemlibra in 2020**

(62 countries reported Hemlibra data)

Country	Number of patients with inhibitors treated with Hemlibra	Number of patients without inhibitors treated with Hemlibra	Total Hemlibra purchased (mg)
Argentina	43	6	
Austria	7	14	
Botswana	1	0	
Cambodia	5	24	
Canada	46	11	516,960
Chile	3	0	8,640
Colombia	77	77	258,570
Costa Rica	16		6,960
Cuba	9	6	40,000
Czech Republic	15	9	60,224
Estonia			21,045
Finland			18,105
France	70	145	1,143,180
Georgia	3	1	19,560
Germany			66,800
Ghana	0	28	0
Greece	11	4	62,520
Hungary	5		
Indonesia	1	1	4,320
Ireland			311,940
Israel	100	80	
Italy			3,150
Japan	73	383	4,053,060
Jordan	2		
Kenya	10	47	0
Korea, Republic of			11,910
Lebanon	2	0	720
Lithuania	4	5	27,510
Madagascar	3	14	
Malaysia	14		3,600

Country	Number of patients with inhibitors treated with Hemlibra	Number of patients without inhibitors treated with Hemlibra	Total Hemlibra purchased (mg)
Maldives	1		
Mali	4	18	
Mexico			74,160
Montenegro	1		5,760
Morocco	3	2	0
New Zealand	18	0	
Nicaragua	4	12	0
Norway	9	0	
Pakistan	30	14	0
Panama	2		1,200
Paraguay	22	1	
Peru	2		
Poland	42	1	160,950
Portugal			76,980
Romania	3		0
Saudi Arabia	41	25	123,760
Senegal	5	2	0
Serbia	12		34,000
Singapore	6	6	20,550
Slovak Republic	2	1	5,850
Slovenia	3		
South Africa	15	3	49,230
Sri Lanka	32		
Sweden	15	2	85,575
Switzerland	1		
Tanzania	17	8	0
Thailand	7	4	0
Uganda	11		
Ukraine*	48	2	180,885
United Kingdom	123	531	2,094,929
United States			17,000,000
Zambia	0	2	

** Data updated after publication. These updates are not reflected in any other calculations or summary tables in this report.*

TABLE 19. **Use of FVIIa and FEIBA**

(89 countries reported FVIIa and FEIBA data)

Country	Numebr of patients treated with recombinant factor VIIa	Precise or Estimate	Total FVIIa purchased (mg)	Number of patients treated FEIBA	Precise or Estimate	Total FEIBA purchased (IU)
Albania	6	Estimate				
Algeria	100	Estimate		22	Estimate	
Angola	0	Precise		0	Precise	
Argentina	55	Estimate		15	Estimate	10,688,000
Australia	0	Estimate	26,142	2	Estimate	2,879,500
Bahamas	0	Precise	0	0	Precise	0
Barbados	2	Estimate		2	Estimate	
Belarus	3	Estimate		3	Estimate	
Belize	0	Precise	0	0	Precise	0
Bolivia	2	Precise		2	Precise	
Botswana	1	Precise		0	Precise	
Brazil	402	Precise	117,798	372	Precise	82,347,000
Burkina Faso			0	1	Precise	0
Cambodia				3	Estimate	
Cameroon	1	Precise		0	Estimate	
Canada	7	Estimate	18,761	16	Estimate	7,471,080
Chile	17	Estimate	2,524	10	Estimate	2,000,000
Colombia	40	Precise	32,930	26	Precise	13,240,000
Costa Rica	10	Precise	800	10	Precise	500,000
Cote d'Ivoire	0	Precise	0	4	Precise	0
Cuba	9	Precise	1,495	0	Precise	
Czech Republic	4	Precise	200	1	Precise	556,500
Djibouti	0	Precise	0	0	Precise	0
Ecuador	1	Estimate		20	Estimate	2,300,000
El Salvador	13	Estimate		0	Estimate	
Eritrea	0	Precise	0	0	Precise	0
Estonia	3	Estimate		1	Estimate	120,000
Ethiopia	0	Estimate	0	0	Estimate	0
Finland	7	Precise	39,100,000	2	Precise	990,000
France	86	Precise	57,984	40	Precise	13,457,500

Country	Numebr of patients treated with recombinant factor VIIa	Precise or Estimate	Total FVIIa purchased (mg)	Number of patients treated FEIBA	Precise or Estimate	Total FEIBA purchased (IU)
Georgia	3	Precise	400	4	Precise	270,000
Germany			7,802			4,583,000
Ghana	0	Precise	0	0	Precise	0
Greece	15	Precise	6,590	7	Precise	220,000
Honduras			0			0
Indonesia	0	Precise		10	Precise	
Iran	40	Estimate	24,473	20	Estimate	4,125,500
Iraq	200	Estimate		0	Precise	
Ireland	9	Estimate	3,459	2	Estimate	388,000
Italy			24,300			6,400,000
Jamaica			0			0
Kenya	1	Precise	0	4	Precise	0
Korea, Republic of			11,057			
Latvia	2	Estimate		2	Estimate	824,000
Lebanon	6	Precise	1,824	2	Precise	0
Lesotho	0	Precise	0	1	Precise	0
Lithuania	6	Precise	400	1	Precise	874,000
Madagascar	0	Precise		0	Precise	
Malaysia	40	Estimate		30	Estimate	
Mauritania	0	Precise	0	0	Precise	0
Mauritius	2	Precise	625	0	Precise	0
Mexico			40,308			9,257,000
Montenegro	0	Precise	0	0	Precise	0
Morocco	0	Precise		0	Precise	
Nepal						413,000
New Zealand	2	Estimate		3	Estimate	
Nicaragua	0	Precise	0	0	Precise	0
Norway	0	Estimate		2	Estimate	
Pakistan	5	Estimate	0	8	Estimate	12,000
Panama	0	Precise	3,016	5	Precise	43,500
Paraguay	2	Estimate		0	Precise	
Philippines	15	Estimate		10	Estimate	0

Country	Numebr of patients treated with recombinant factor VIIa	Precise or Estimate	Total FVIIa purchased (mg)	Number of patients treated FEIBA	Precise or Estimate	Total FEIBA purchased (IU)
Poland			36,800			30,117,000
Portugal			6,161			960,000
Qatar	1	Precise		0	Precise	
Romania			5,496,000	94	Estimate	8,901,500
Russia			196,168			57,023,000
Saudi Arabia	80	Estimate		30	Estimate	
Senegal	1	Precise	0	10	Precise	0
Serbia	13	Precise	3,993	0	Precise	479,000
Singapore	2	Precise		2	Precise	
Slovak Republic	5	Precise	2,700	3	Precise	1,600,000
Slovenia	3	Precise		0	Precise	
South Africa						4,458,000
Sri Lanka	40	Estimate		80	Estimate	846,500
Sudan				6	Precise	115,000
Suriname	0	Precise	0	0	Precise	0
Sweden	14	Precise	5,982	5	Precise	1,382,500
Syria	3	Estimate		0	Precise	0
Tanzania	0	Estimate	0	4	Estimate	0
Thailand	14	Precise	843	23	Precise	1,252,500
Tunisia			1,028			1,254,000
United Kingdom	93	Precise	25,433	23	Precise	9,583,650
United States			300,000,000			65,000,000
Uzbekistan	0	Precise	0	0	Precise	0
Venezuela	4	Precise	0	2	Precise	0
Vietnam			1,590			1,820,500
Zimbabwe	0	Precise		0	Precise	

TABLE 20. **Use of VWD products 2020**

(52 countries provided data on VWD products)

Country	Number of vWD patients treated with plasma	Number of vWD patients treated with Cryoprecipitate	Number of vWD patients treated with Plasma-derived Concentrate	Number of vWD patients treated with DDAVP	Number of vWD patients treated with recombinant concentrate	Number of vWD patients treated with tranexamic acid
Albania	1	1		1		2
Argentina	0	0	14			
Australia	0	0	213			
Bahamas	0	0		0		0
Botswana	0		2			7
Brazil	0	0	1251	149		
Cambodia	2		2			4
Cameroon					205	
Canada			245	67	1	65
Colombia	0	0	220	100	25	350
Cote d'Ivoire	1	0		3		3
Cuba		15	12	24		
Czech Republic	0	0	108	2		
Djibouti						2
Ecuador			99			99
France	0		137	45	24	
Ghana	1	1	6	0	0	3
Greece			105	108	3	250
Honduras	0	0	4			
Indonesia			2			
Iran	1		432			9
Iraq	0					
Jamaica	3	3				
Kenya	0	10	5	15	0	0
Lebanon			45			
Madagascar	1					2
Malaysia	0	0	25			73
Mali						18
Mauritania	1		1		1	

Country	Number of vWD patients treated with plasma	Number of vWD patients treated with Cryoprecipitate	Number of vWD patients treated with Plasma-derived Concentrate	Number of vWD patients treated with DDAVP	Number of vWD patients treated with recombinant concentrate	Number of vWD patients treated with tranexamic acid
Mauritius	0	0	NA	0	NA	0
Montenegro	0	0	0	1		0
Morocco	57		11			53
Mozambique	2					
Netherlands	0	0	367	180	13	
New Zealand			2			
Norway	0	0				
Panama			521			
Poland	0	0				
Saudi Arabia	18	13	200	100	0	200
Senegal	9		7		2	13
Singapore	0	0	28	0		15
Slovak Republic	0		138	10		80
Slovenia			3	13		
South Africa	0	0	40	225		500
Switzerland	0	0	36		0	
Tanzania	5				3	5
Thailand	3	34	29	46		60
Uganda			3			3
United Kingdom			700		14	
Uzbekistan	35	32				12
Venezuela	8	5	120	150		300
Vietnam	2	50		10		

Annual Global Survey **2020**

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 data provided for this survey?	**Check all those that apply** ☐ Hemophilia Society and/or NMO registry or database ☐ Hospital(s)/HTC(s) registry or database ☐ Health Ministry registry or database ☐ National registry ☐ National Insurance data ☐ 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 ☐ Clinician or clinical staff ☐ Other (please describe):
Have all the identified patients in your country been included in this report? If not, please explain.	Yes ☐ No ☐ Please explain:
Does your country have an established national registry for collecting data on patients with bleeding disorders?	Yes ☐ No ☐

Please Click Here **to validate Data source**

Annual Global Survey **2020**

B. Identified Patients

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

(Please DO NOT estimate or guess)	**Total**	**Male**	**Female**	**Sex 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	☐	☐	☐	☐

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. Number of identified people with hemophilia by sex 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 % of the normal amount of clotting factor has **mild** hemophilia.
- A person (male or female) with between 1-5 % of the normal amount of clotting factor has **moderate** hemophilia.
- A person (male or female) with less than 1 % 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 ☐

7. 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 ☐

8. INHIBITORS: Number of identified people with hemophilia with current clinically significant inhibitors in 2020. (Patients who do not respond to normal treatment.)

Type of hemophilia	Total number with active inhibitors	New cases of inhibitors in 2020	No Data
Hemophilia A			☐
Hemophilia B			☐

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

9 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.

9 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
Emicizumab (Hemlibra)	☐		☐

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

9 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
Emicizumab (Hemlibra)	☐		☐

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

10. 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)	☐		☐
Nasal	☐		☐
IV/Subcutaneous	☐		☐
Recombinant concentrate	☐		☐
Transexamic acid	☐		☐

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

11. HIV infection

	Hemophilia A or B, or type unknown	von Willebrand disease	Other hereditary bleeding disorders	No data
Total number of people living with HIV				☐
New HIV infections in 2020				☐

12. Hepatitis C infection

	Hemophilia A or B, or type unknown	von Willebrand disease	Other hereditary bleeding disorders	No data
Total number of people infected with hepatitis C[1]				☐
Total number of people with currently active hepatitis C[2]				☐
New hepatitis C infections in 2020				☐

[1]Hepatitis C antibody positive at any time

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

13. Number and cause of deaths of people with bleeding disorders (January 1-December 31, 2020)

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	No data
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 Hemophilia Treatment Centre (HTC) as a medical centre providing clinical care and serving the needs for people with hemophilia and related disorders (including diagnosis and treatment). Please provide the number of all such centres in your country. Please also indicate how many of those are Hemophilia Comprehensive Care Centres. These are defined as a hemophilia treatment centre providing comprehensive care involving multidisciplinary medical services necessary for the diagnosis, treatment and management of the condition and its complications. Comprehensive care includes access to hospital-based nursing staff, physical therapy services, social workers, dental services, obstetric and gynecological services, psychosocial services, home therapy, inhibitor care and immune tolerance services, genetics laboratory, genetic counselling, HIV and hepatitis care. They can also include 24/7 availability of expert care (i.e. a doctor with hemophilia expertise is on call at all times).

14. How many **hemophilia treatment centres** are there in total in your country?	
How many of the **hemophilia treatment centres** you have indicated above are Hemophilia Comprehensive Care Centres?	
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.

15. 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 **percentage** of identified people with **von Willebrand disease (VWD) type 3** are on prophylaxis?		Precise: ☐ Estimate: ☐	Not known ☐

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 <u>new</u> patients who started ITI during the last year. Please indicate if these #s are precise or an estimate.

16. 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 **<u>started</u>** ITI treatment during the last year?		Precise: ☐ Estimate: ☐	Not known ☐

Recombinant factor VIIa and FEIBA are administered to treat and prevent bleeding in people with hemophilia (with Factor VIII or IX deficiency) who have developed antibodies against replacement coagulation factor.

17 a) What is the total number of patients with inhibitors who received factor VIIa during the last year?		Precise: ☐ Estimate: ☐	Not known ☐
17 b) What is the total number of patients with inhibitors who received FEIBA during the last year?		Precise: ☐ Estimate: ☐	Not known ☐

Please Click Here **to validate Care section**

D. The Cost and Use of Factor Concentrates

Please enter only numbers and do not use punctuation or special characters.

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 2020 (excluding donated factor)?		☐		☐
Plasma derived: How many international units of **plasma-derived** concentrates were used in your country in 2020 (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 2020 (excluding donated factor)?		☐		☐
Recombinant, extended half-life: How many international units of **recombinant** concentrates**, extended half-life** were used in your country in 2020 (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 2020?		☐		☐

18 C. Annual usage of purchased Hemlibra (Emicizumab)	**Amount (mg)**	**Not known**
How many milligrams (mg) of Hemlibra were purchased in your country in 2020? (Excluding donated product)		☐

18 D. Annual usage of purchased factor VIIa and FEIBA	**Amount**	**Not known**
How many milligrams (mg) of FVIIa were purchased in your country in 2020? (excluding donated product)	**(mg)**	☐
How many international units (IU) of FEIBA were purchased in your country in 2020? (excluding donated product)	**(ui)**	☐

Annual Global Survey **2020**

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:	Not data ☐

Please Click Here **to validate Factors section**

19. Factor VIII Concentrates used in 2020

(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)	
☐	Afstyla	CSL Behring	
☐	Aleviate	CSL Behring	
☐	Alphanate	Grifols	
☐	Amofil	Sanquin OY	
☐	Bioclot A	Biofarma	
☐	Beriate P	CSL Behring	
☐	BIOSTATE	CSL Bioplasma	
☐	Cluvot	CSL Behring	
☐	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	
☐	NovoThirteen	NovoNordisk	
☐	Nuwiq	Octapharma	
☐	Octanate	Octapharma	
☐	Octanativ-M	Octapharma	
☐	Octavi SD	Octapharma	
☐	Octofactor	Generium/Pharmstandart	
☐	Optivate	Bio Products Laboratory	
☐	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	
☐	Wilate	Octapharma	
☐	Xyntha	Pfizer (Wyeth)	
☐	Other:		

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

20. Factor IX Concentrates used in 2020

(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	
☐	Idelvion	CSL Behring	
☐	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	
☐	Rebynin	NovoNordisk	
☐	Refixia	NovoNordisk	
☐	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 2020

(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:		

23. Non-factor products used in 2020

(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
☐	Emicizumab (Hemlibra)	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.

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 half-life.

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

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

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

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

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

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

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

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

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

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

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

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

PWH: Person with hemophilia

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

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

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

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

REFERENCES

1. World Health Organization. 2019. Definition of regional groupings. https://www.who.int/healthinfo/global_burden_disease/definition_regions/en/. Accessed on March 10, 2019.
2. Soucie JM, Evatt B, Jackson D; Hemophilia Surveillance System Project Investigators. Occurrence of hemophilia in the United States. Am J Hematol. 1998;59:288-94.
3. Stonebraker JS, Bolton-Maggs PH, Soucie JM, et al. A study of variations in the reported haemophilia A prevalence around the world. Haemophilia. 2010;16:20-32.
4. Stonebraker JS, Bolton-Maggs PH, Soucie JM, et al. A study of variations in the reported haemophilia B prevalence around the world. Haemophilia. 2012;18:e91-4.
5. Calvez T, Chambost H, Claeyssens-Donadel S, et al; FranceCoag Network. Recombinant factor VIII products and inhibitor development in previously untreated boys with severe hemophilia A. Blood. 2014;124:3398-408.
6. Iorio A, Stonebraker JS, Brooker M, et al; Data and Demographics Committee of the World Federation of Hemophilia. Measuring the quality of haemophilia care across different settings: a set of performance indicators derived from demographics data. Haemophilia. 2017;23:e1-7.
7. Iorio A, Stonebraker JS, Chambost H, et al. Establishing the prevalence and prevalence at birth of hemophilia in males. Ann Intern Med. 2019;171:540-546.

WFH

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