ANNUAL GLOBAL SURVEY

World Federation of Hemophilia Report on the

Annual Global Survey 2021

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

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INTRODUCTION TO THE REPORT ON THE ANNUAL GLOBAL SURVEY 2021

The Report on the Annual Global Survey (AGS) 2021 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 2021 data can be found on the website at: **https://wfh.org/data-collection/#ags**.

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 2021

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 2021. 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 818,928, of which about 278,200 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 287,708 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

Members:
Magdy El Ekiaby
Emna Gouider
Alfonso Iorio
Mike Makris
Jamie O'Hara
Glenn Pierce
Michael Recht

Annual Global Survey Reviewers:
Paula Bolton-Maggs
Randall Curtis
Brian O'Mahony
Suely Rezende
Alok Srivastava

PART 1:
Global Data 1999–2021

GLOBAL REPRESENTATION OVER TIME (1999–2021)

Since 1999, there have been 145 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 provides a more complete representation of the current state of patient identification globally.

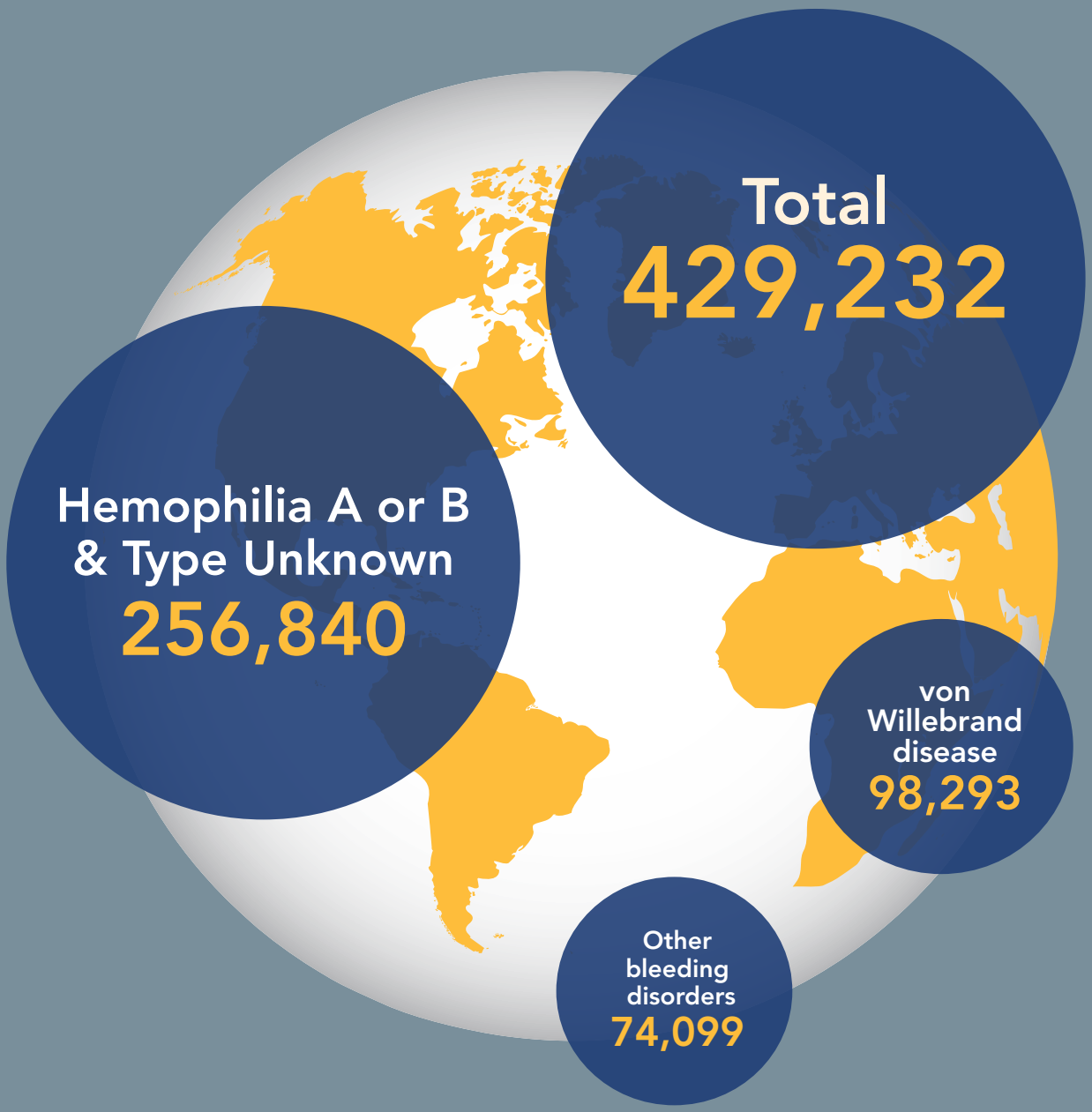


FIGURE A1. **Identified patients over time – all bleeding disorders**

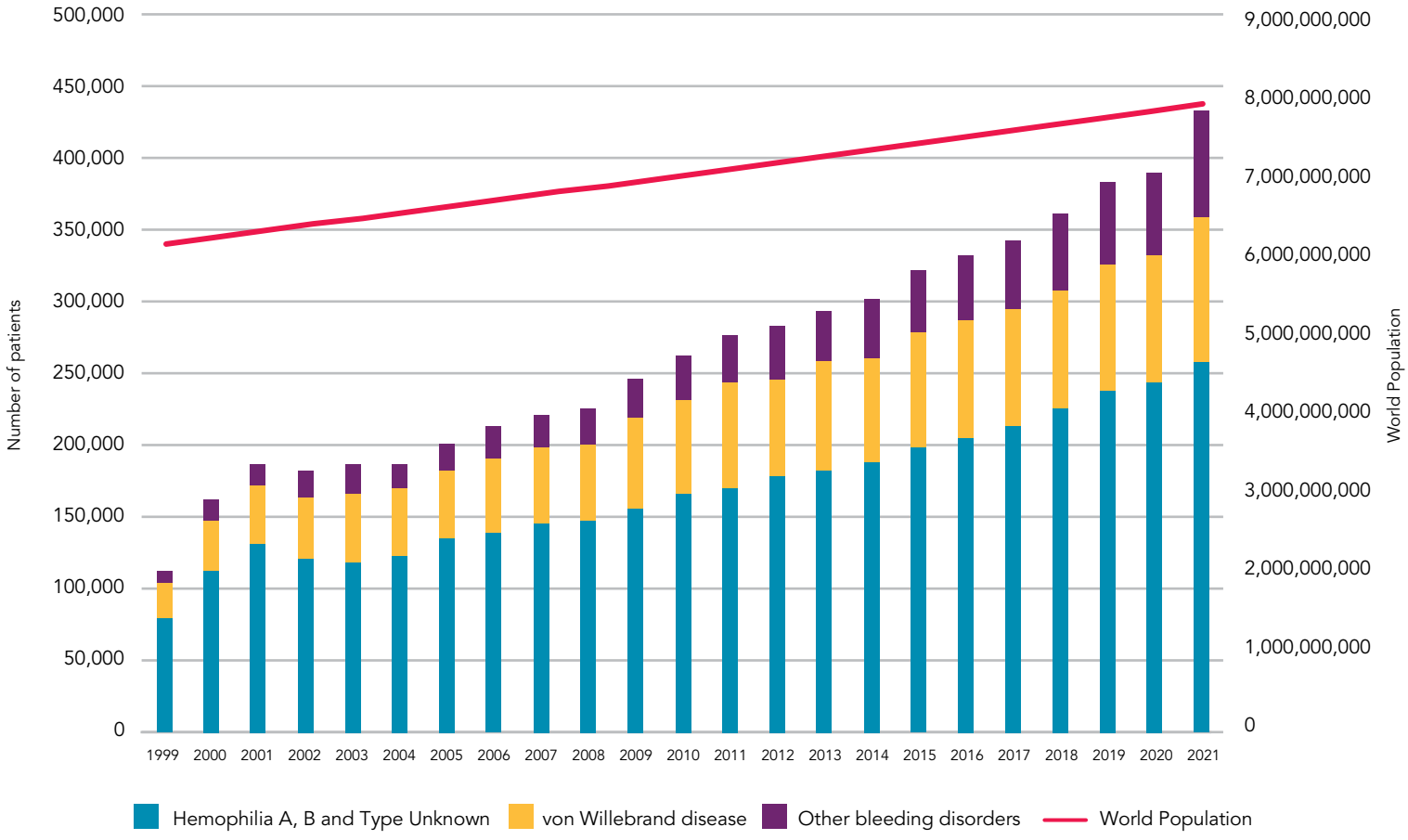


FIGURE A2. **Identified patients over time – other rare bleeding disorders**

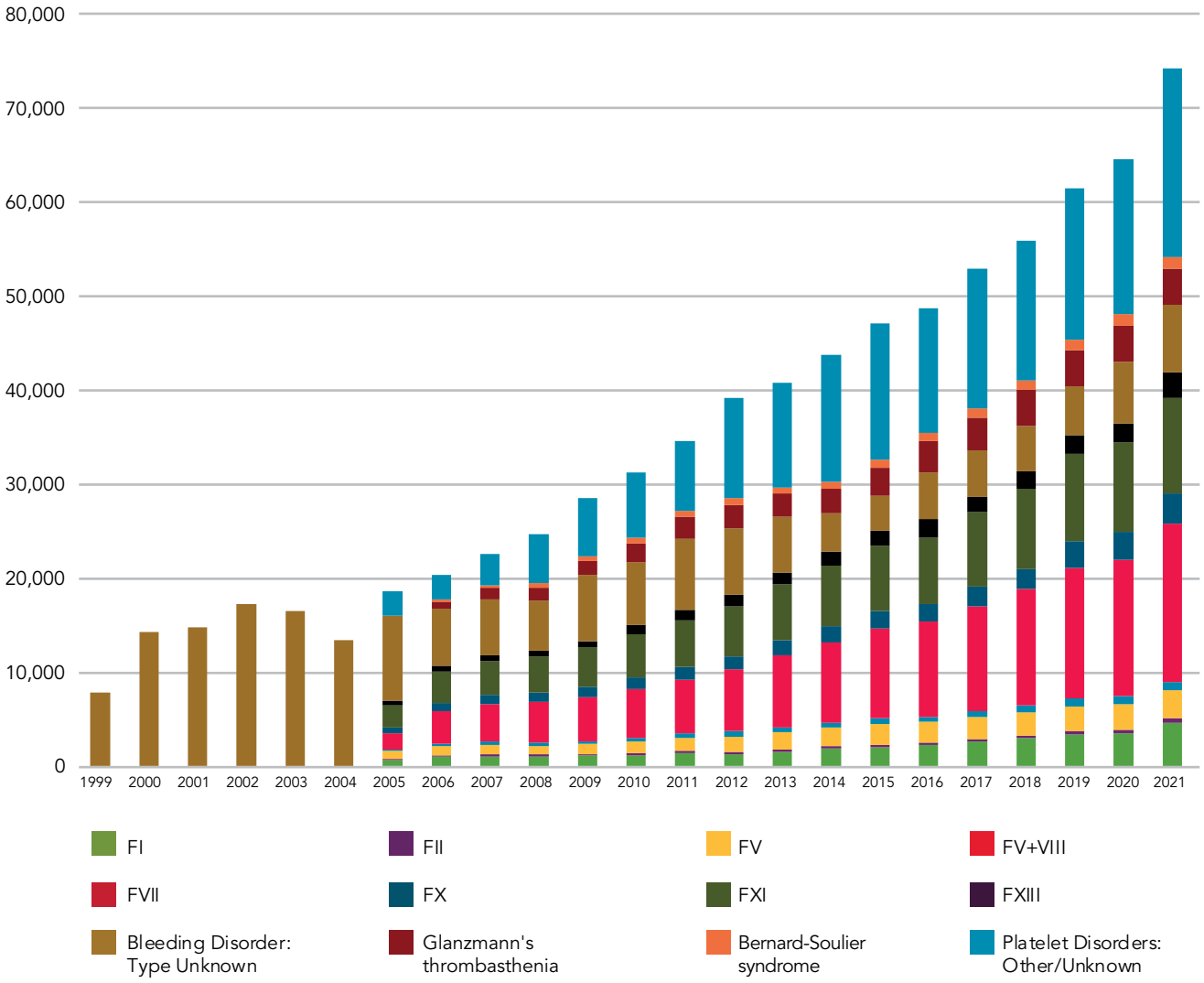


TABLE 1. **National member organizations and their latest year of reporting.**

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 2021 survey report, 118 countries submitted data and can be found in **BOLD** in the table below.

Country	Last year of submission	Total number of submissions
Afghanistan	**2021**	**6**
Albania	**2021**	**18**
Algeria	**2021**	**18**
Angola	**2021**	**2**
Argentina	**2021**	**22**
Armenia	**2021**	**12**
Australia	**2021**	**23**
Austria	**2021**	**17**
Azerbaijan	2018	14
Bahamas	**2021**	**4**
Bahrain	**2021**	**6**
Bangladesh	**2021**	**23**
Barbados	**2021**	**5**
Belarus	2020	14
Belgium	**2021**	**21**
Belize	**2021**	**15**
Benin	**2021**	**2**
Bolivia	**2021**	**10**
Bosnia and Herzegovina	2019	6
Botswana	**2021**	**5**
Brazil	**2021**	**22**
Bulgaria	2018	10
Burkina Faso	**2021**	**6**
Cambodia	**2021**	**15**
Cameroon	**2021**	**15**
Canada	**2021**	**22**
Chile	**2021**	**14**
China	**2021**	**13**
Colombia	**2021**	**22**
Congo, Republic of the	**2021**	**1**
Costa Rica	**2021**	**22**
Côte d'Ivoire	**2021**	**14**
Croatia	**2021**	**7**
Cuba	**2021**	**19**

Country	Last year of submission	Total number of submissions
Cyprus	2013	7
Czech Republic	**2021**	**16**
Denmark	2018	14
Djibouti	2020	1
Dominican Republic	**2021**	**20**
Ecuador	2020	15
Egypt	**2021**	**20**
El Salvador	**2021**	**9**
Eritrea	**2021**	**14**
Estonia	**2021**	**13**
Ethiopia	**2021**	**11**
Finland	**2021**	**17**
France	**2021**	**19**
Georgia	**2021**	**20**
Germany	**2021**	**23**
Ghana	**2021**	**11**
Greece	2020	21
Guatemala	2019	10
Guyana	**2021**	**5**
Honduras	**2021**	**20**
Hong Kong	**2021**	**4**
Hungary	**2021**	**20**
Iceland	2007	6
India	**2021**	**21**
Indonesia	**2021**	**18**
Iran	**2021**	**22**
Iraq	**2021**	**18**
Ireland	**2021**	**23**
Israel	**2021**	**16**
Italy	2020	13
Jamaica	**2021**	**12**
Japan	**2021**	**22**
Jordan	**2021**	**16**
Kazakhstan	2008	1

Country	Last year of submission	Total number of submissions
Kenya	**2021**	**20**
Korea, Republic of	**2021**	**23**
Kuwait	**2021**	**2**
Kyrgyzstan	**2021**	**8**
Latvia	**2021**	**23**
Lebanon	**2021**	**12**
Lesotho	**2021**	**15**
Lithuania	**2021**	**22**
Luxembourg	**2021**	**4**
Macedonia	2018	9
Madagascar	**2021**	**6**
Malawi	**2021**	**6**
Malaysia	**2021**	**21**
Maldives	**2021**	**8**
Mali	**2021**	**6**
Malta	**2021**	**6**
Mauritania	2020	4
Mauritius	**2021**	**11**
Mexico	**2021**	**20**
Moldova	2017	11
Mongolia	**2021**	**15**
Montenegro	**2021**	**7**
Morocco	**2021**	**9**
Mozambique	2020	4
Myanmar	2019	3
Namibia	2020	2
Nepal	**2021**	**22**
Netherlands	**2021**	**17**
New Zealand	**2021**	**23**
Nicaragua	2020	16
Nigeria	**2021**	**14**
Norway	**2021**	**17**
Oman	2016	6
Pakistan	**2021**	**21**
Palestine	**2021**	**11**
Panama	**2021**	**20**
Paraguay	**2021**	**9**
Peru	2020	11
Philippines	**2021**	**19**

Country	Last year of submission	Total number of submissions
Poland	**2021**	**23**
Portugal	**2021**	**23**
Qatar	**2021**	**11**
Romania	**2021**	**18**
Russia	**2021**	**22**
Saudi Arabia	**2021**	**14**
Senegal	**2021**	**17**
Serbia	**2021**	**15**
Sierra Leone	1999	1
Singapore	**2021**	**13**
Slovakia	**2021**	**20**
Slovenia	**2021**	**16**
South Africa	**2021**	**22**
Spain	**2021**	**15**
Sri Lanka	**2021**	**13**
Sudan	**2021**	**18**
Suriname	**2021**	**5**
Sweden	**2021**	**17**
Switzerland	2020	17
Syria	**2021**	**11**
Tajikistan	2020	3
Tanzania, United Republic of	**2021**	**10**
Thailand	**2021**	**21**
Togo	**2021**	**10**
Trinidad and Tobago	**2021**	**2**
Tunisia	**2021**	**17**
Turkey	2014	16
Uganda	**2021**	**11**
Ukraine	**2021**	**14**
United Arab Emirates	2015	1
United Kingdom	**2021**	**22**
United States of America	**2021**	**22**
Uruguay	**2021**	**14**
Uzbekistan	**2021**	**19**
Venezuela	**2021**	**23**
Vietnam	**2021**	**19**
Zambia	**2021**	**7**
Zimbabwe	**2021**	**17**

PART 2:
2021 Data

KEY NUMBERS FROM THE REPORT ON THE ANNUAL GLOBAL SURVEY 2021

For all tables and graphs from this point onwards, the analyses were done using only data from countries that responded in 2021.

118

NUMBER OF COUNTRIES
in this survey

RESPONSE RATE
from WFH National Member Organizations

80%
(118/147)

386,966

NUMBER OF IDENTIFIED PATIENTS

233,577	People with hemophilia
185,318	Hemophilia A
37,998	Hemophilia B
10,261	Hemophilia type unknown
89,848	von Willebrand disease
63,541	Other bleeding disorders

FACTOR VIII USAGE PER CAPITA

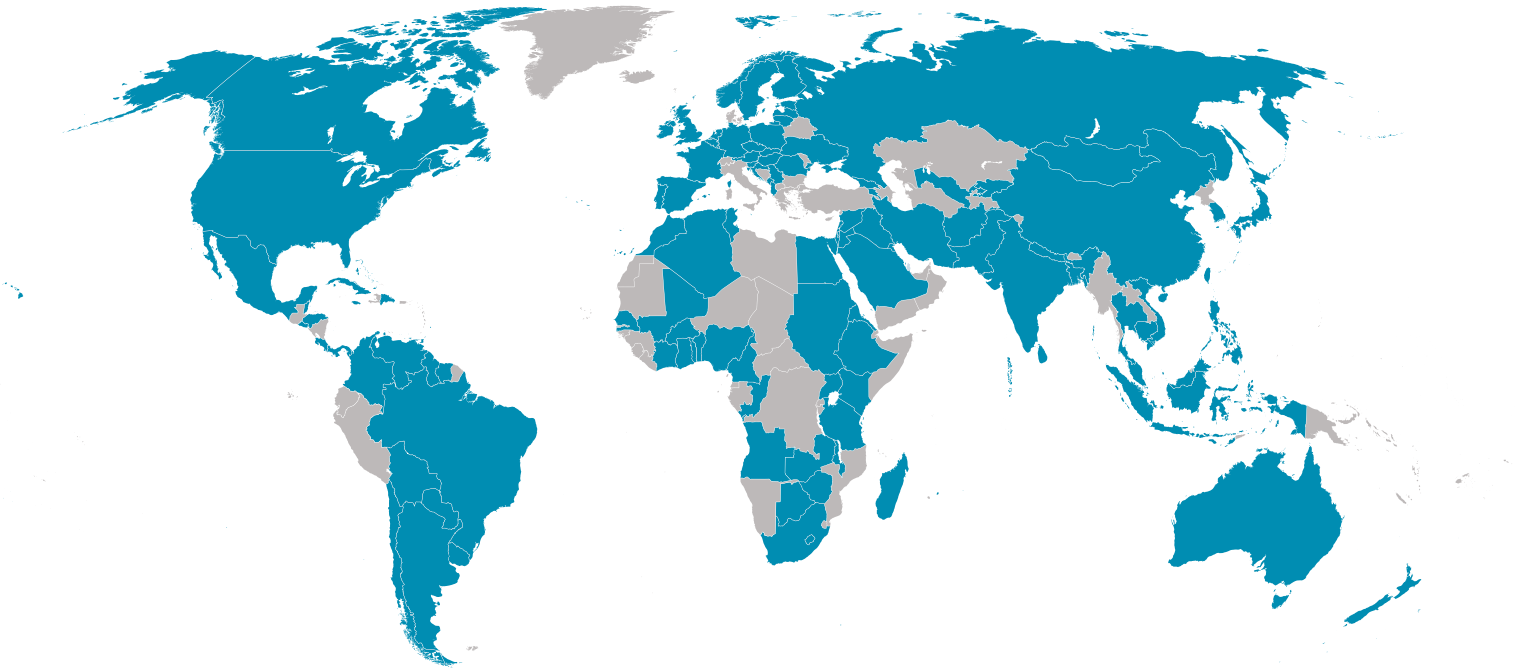
1.049 IU (0.136-4.667) Median (IQR)
102 countries

FACTOR IX USAGE PER CAPITA

0.184 IU (0.021-0.708) Median (IQR)
95 countries

COUNTRY REPRESENTATION

Annual Global Survey 2021



2021 Data Respondents

The WFH has a total of 147 national member organizations (NMOs). The Report on the Annual Global Survey 2021 includes data from 118 NMOs.

FIGURE B1. **Country representation by region**

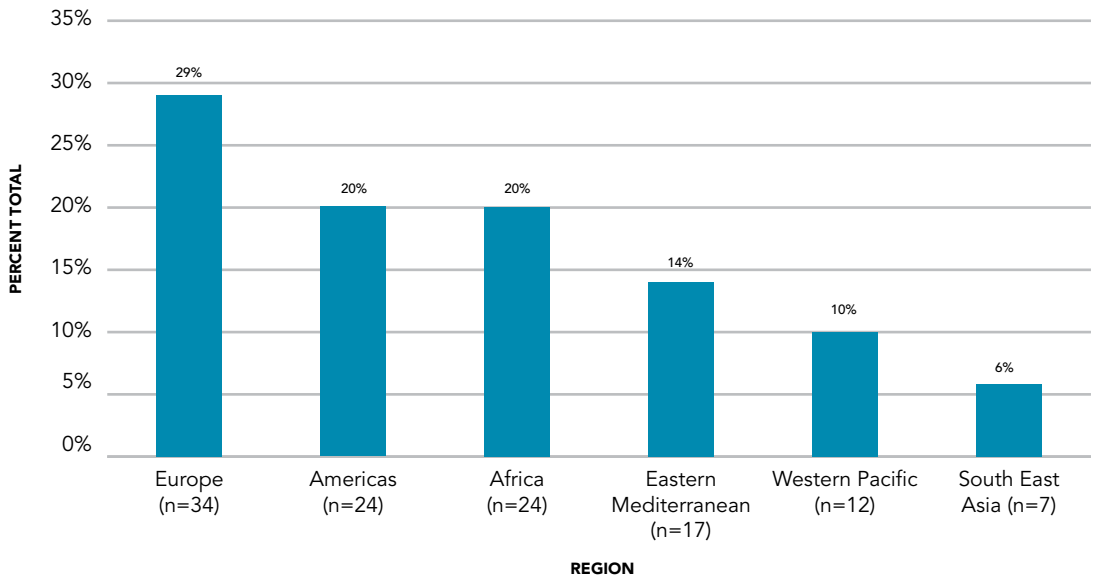
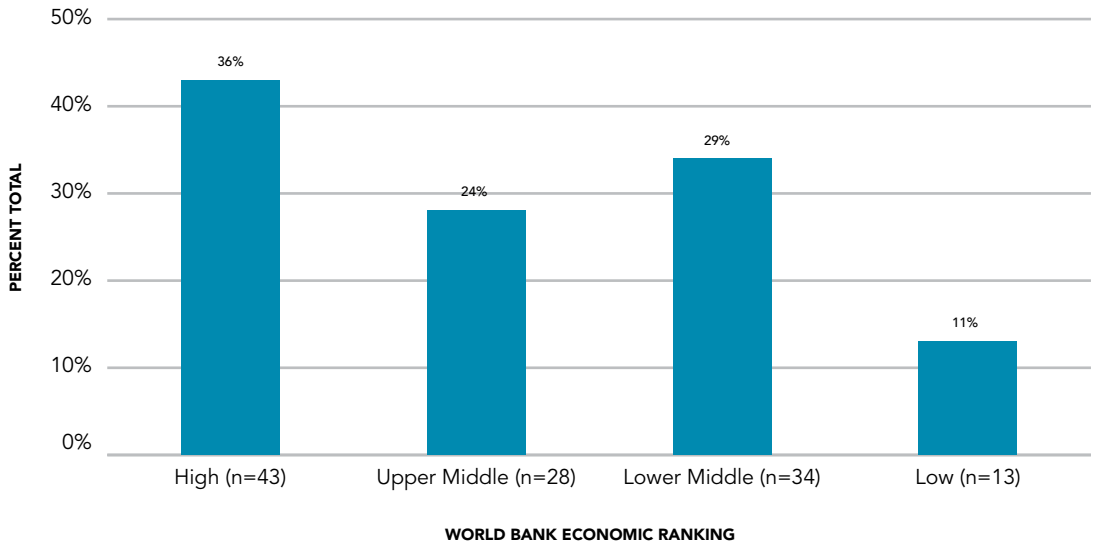


FIGURE B2. **Country representation by gross national income**



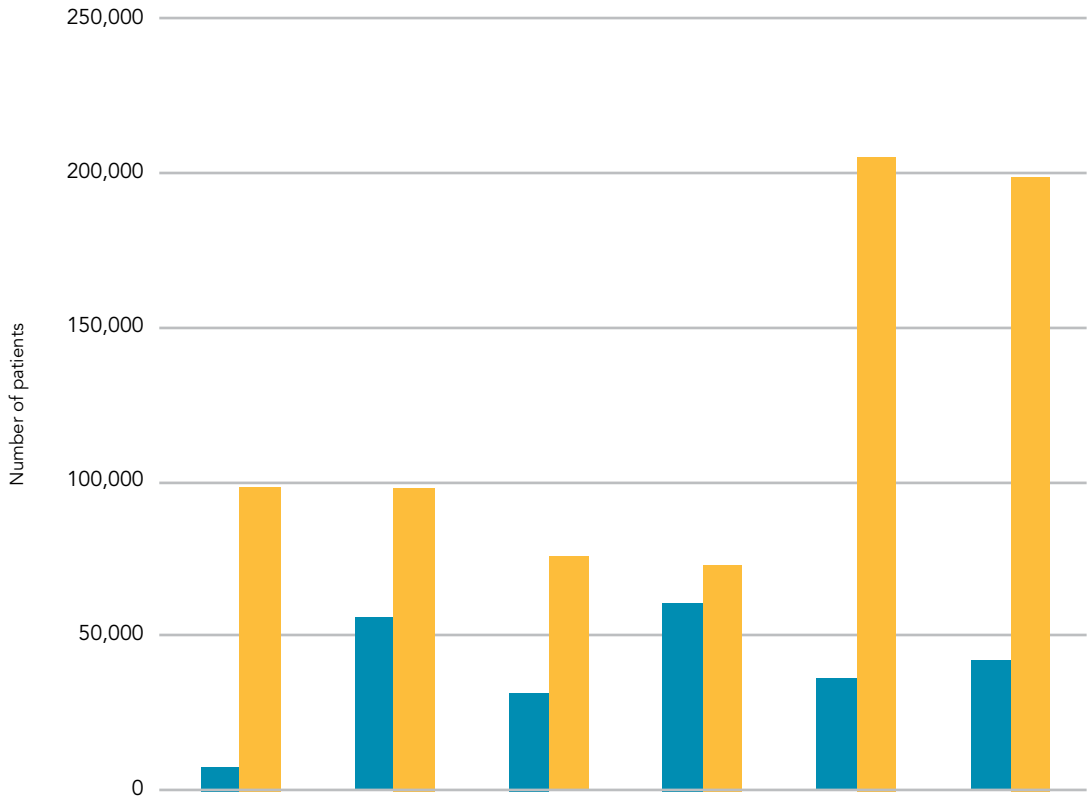
Economic category based on The World Bank Group 2021 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,085; C lower middle income, $1,086-$4,255; B upper middle income, $4,256-$13,205; and A high income, $13,205 or more.

REPORT ON THE ANNUAL GLOBAL SURVEY 2021 SUMMARY DEMOGRAPHICS

TABLE 2. **Demographics**

	2021 Total
Number of countries in this survey	**118**
World population covered by countries in this survey report	**7,138,671,532**
Total number of people with bleeding disorders identified	**386,966**
Number of people identified with Hemophilia	**233,577**
Number of people with hemophilia A	**185,318**
Number of people with hemophilia B	**37,998**
Number of people with hemophilia type unknown or type not reported	**10,261**
Number of people identified with VWD	**89,848**
Number of people identified with Other Bleeding Disorders	**63,541**
Number of hemophilia A patients with clinically identified inhibitors	**6,404**
Number of hemophilia B patients with clinically identified inhibitors	**352**

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	7,385	56,544	32,545	60,288	34,673	42,142
Expected number of patients	97,946	97,932	75,124	72,227	204,653	198,109
Percent of identified patients	**8%**	**58%**	**43%**	**83%**	**17%**	**21%**

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 2021**

(102 countries reported FVIII data)

	FACTOR USAGE
Mean (SD) global per capita factor VIII usage	**2.489 IU (2.999)**
Median global per capita factor VIII usage	**1.049 IU**
Interquartile range (IQR) global per capita factor VIII usage	**4.531 IU (0.136-4.667)**
Total consumption of factor VIII concentrates	**9,800,101,854 IU**

TABLE 4. **Factor IX usage 2021**

(95 countries reported FIX data)

	FACTOR USAGE
Mean (SD) global per capita factor IX usage	**0.430 IU (0.590)**
Median global per capita factor IX usage	**0.184 IU**
Interquartile range (IQR) global per capita factor IX usage	**0.687 IU (0.021-0.708)**
Total consumption of factor IX concentrates	**1,663,675,681 IU**

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).

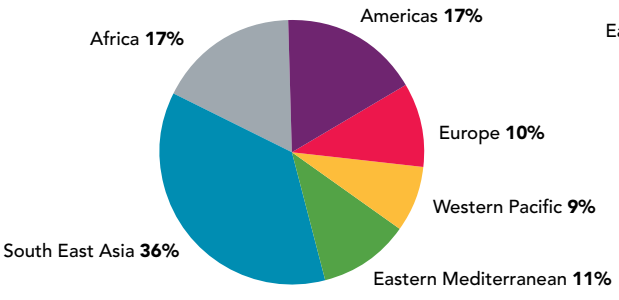
TABLE 5. **Factor use in 2020 and 2021**

	2020	2021
FACTOR VIII (93 countries reported FVIII data in both 2020 and 2021)		
Mean (SD) global per capita factor VIII usage	2.487 IU (3.022)	2.531 IU (3.059)
Median global per capita factor VIII usage	0.945 IU	1.037 IU
Interquartile range (IQR) global per capita factor VIII usage	4.153 IU (0.129–4.281)	4.578 IU (4.751–0.137)
FACTOR IX (86 countries reported factor IX data in both 2020 and 2021)		
Mean (SD) global per capita factor IX usage	0.437 IU (0.623)	0.430 IU (0.598)
Median global per capita factor IX usage	0.155 IU	0.180 IU
Interquartile range (IQR) global per capita factor IX usage	0.693 IU (0.656-0.017)	0.653 IU (0.647-0.021)

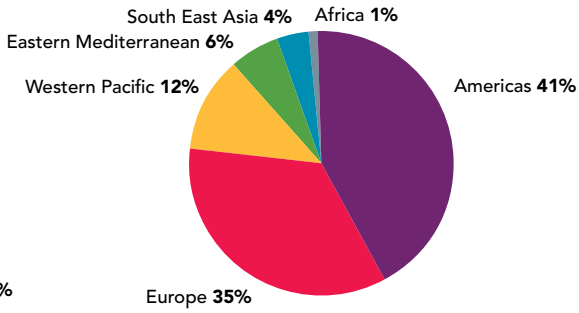
This table show the mean, median and interquartile range (IQR) of per capita factor usage for the countries that reported in both years indicated. The standard deviation (SD) describes the amount of variation of dispersion from the mean. The interquartile range (IQR) describes the middle 50% of reported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

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

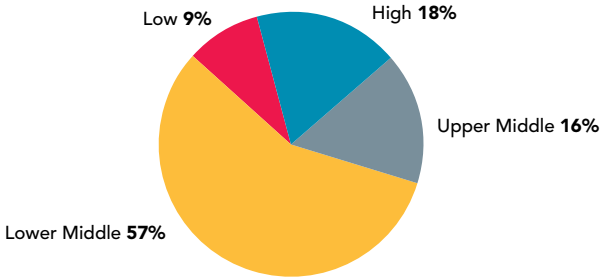
Population by region



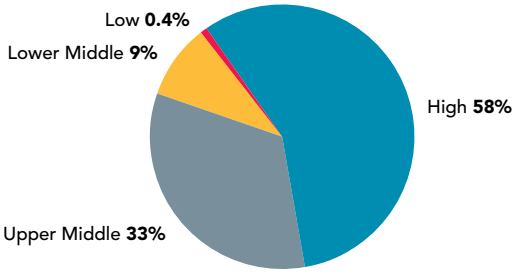
Total FVIII IU by region



Population by gross national income



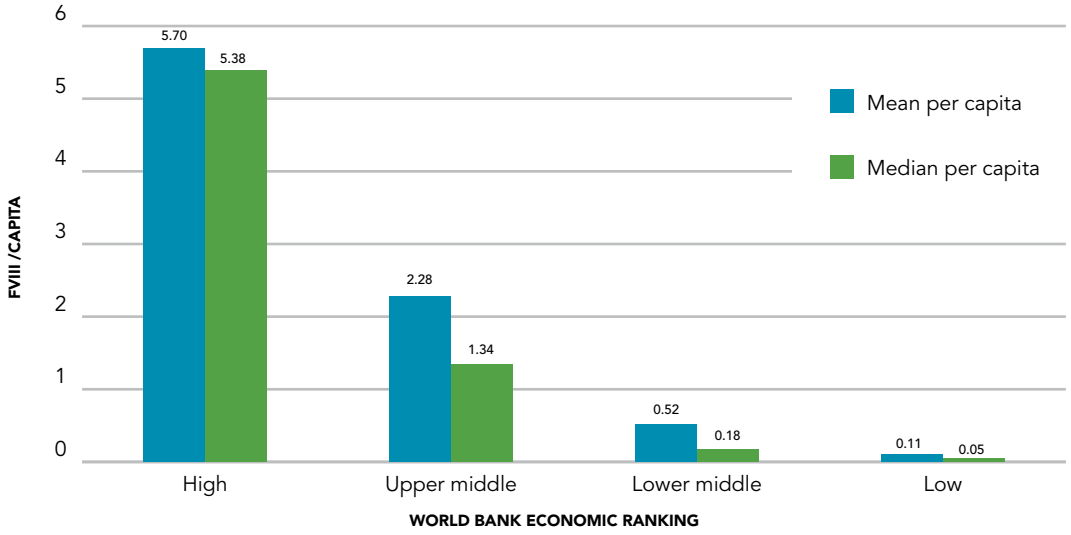
Total FVIII IU by gross national income



Economic category based on The World Bank Group 2021 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,085; C lower middle income, $1,086-$4,255; B upper middle income, $4,256-$13,205; and A high income, $13,205 or more.

FIGURE E. **Mean and median global factor VIII per capita 2021**

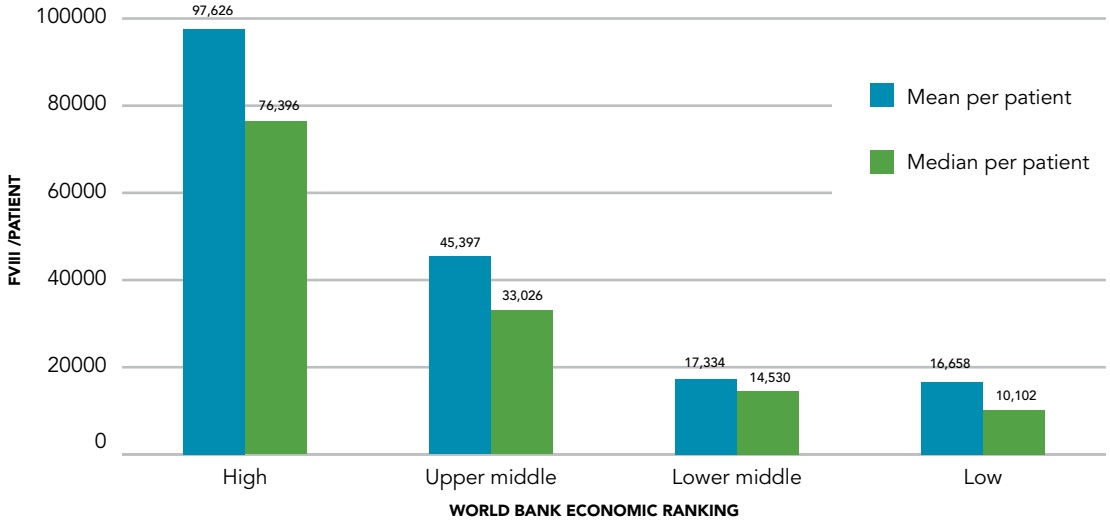
(Data from 101 countries.)



Economic category based on The World Bank Group 2021 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,085; C lower middle income, $1,086-$4,255; B upper middle income, $4,256-$13,205; and A high income, $13,205 or more.

FIGURE F. **Mean and median global factor FVIII per patient 2021**

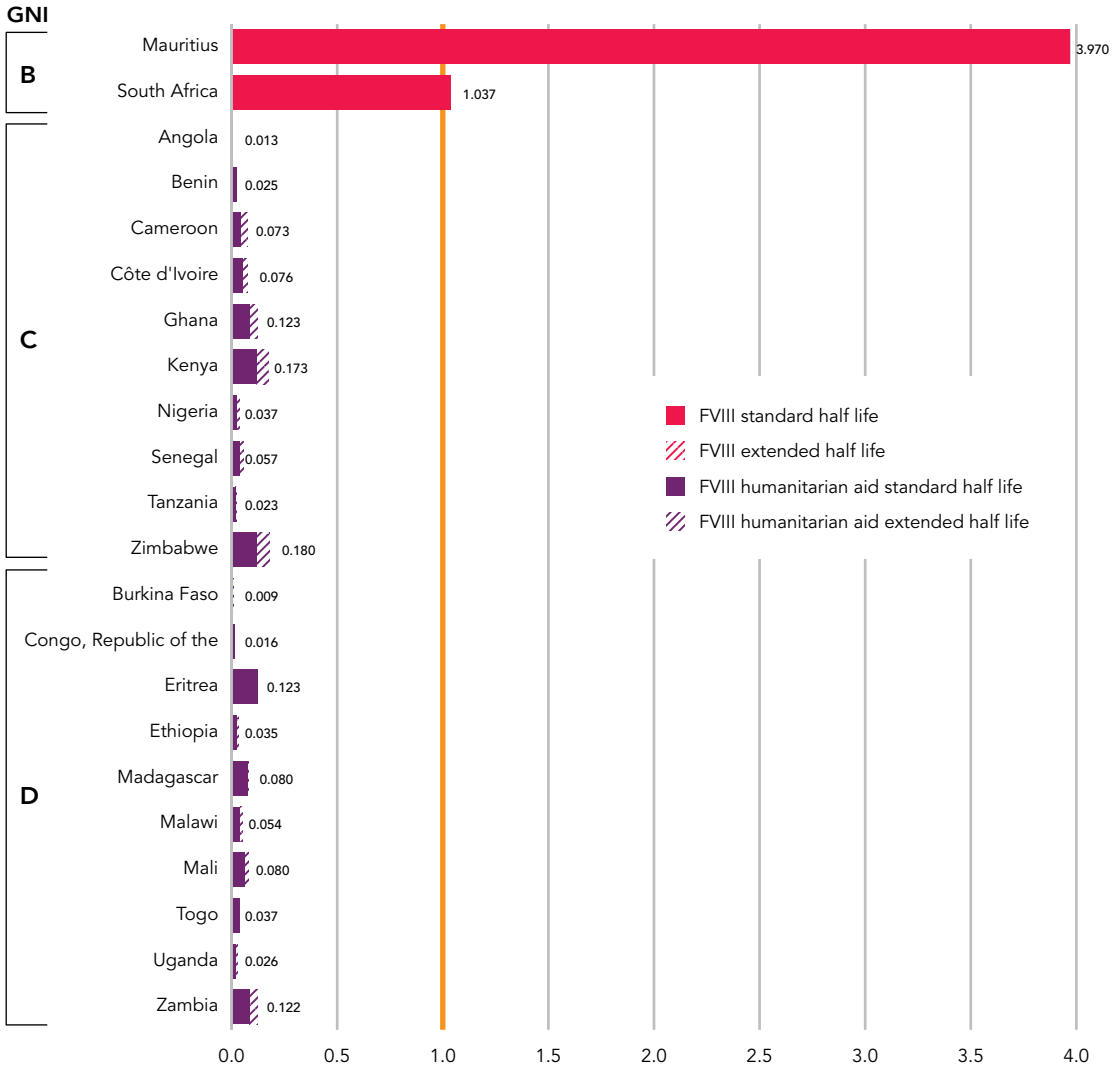
(Data from 101 countries.)



Economic category based on The World Bank Group 2021 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,085; C lower middle income, $1,086-$4,255; B upper middle income, $4,256-$13,205; and A high income, $13,205 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.

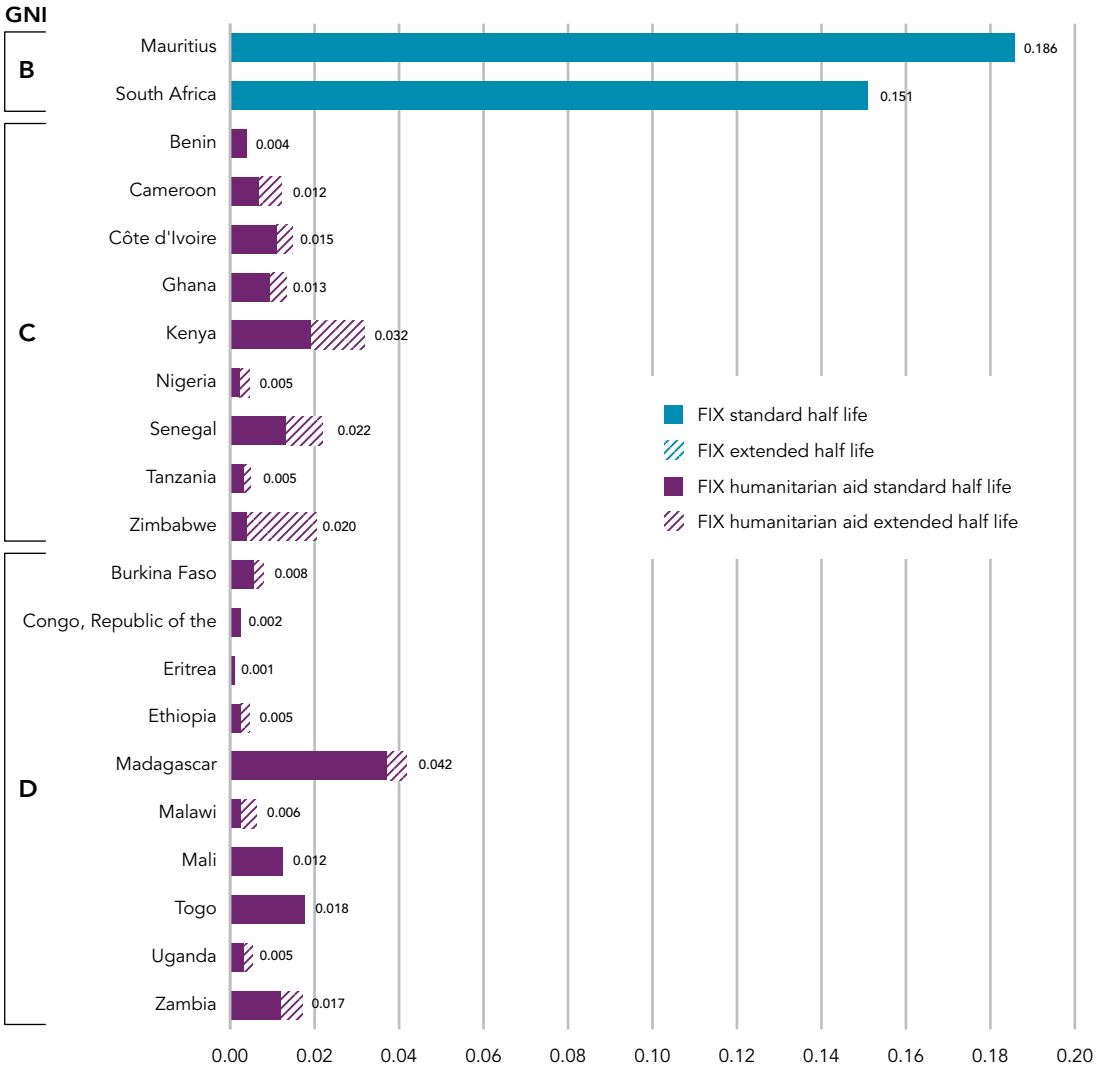
FIGURE G1a. **Mean per capita factor VIII use in 2021 – regional and GNI comparisons of IU/total population: Africa**



Economic category based on The World Bank Group 2021 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,085; C lower middle income, $1,086-$4,255; B upper middle income, $4,256-$13,205; and A high income, $13,205 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 2021 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.

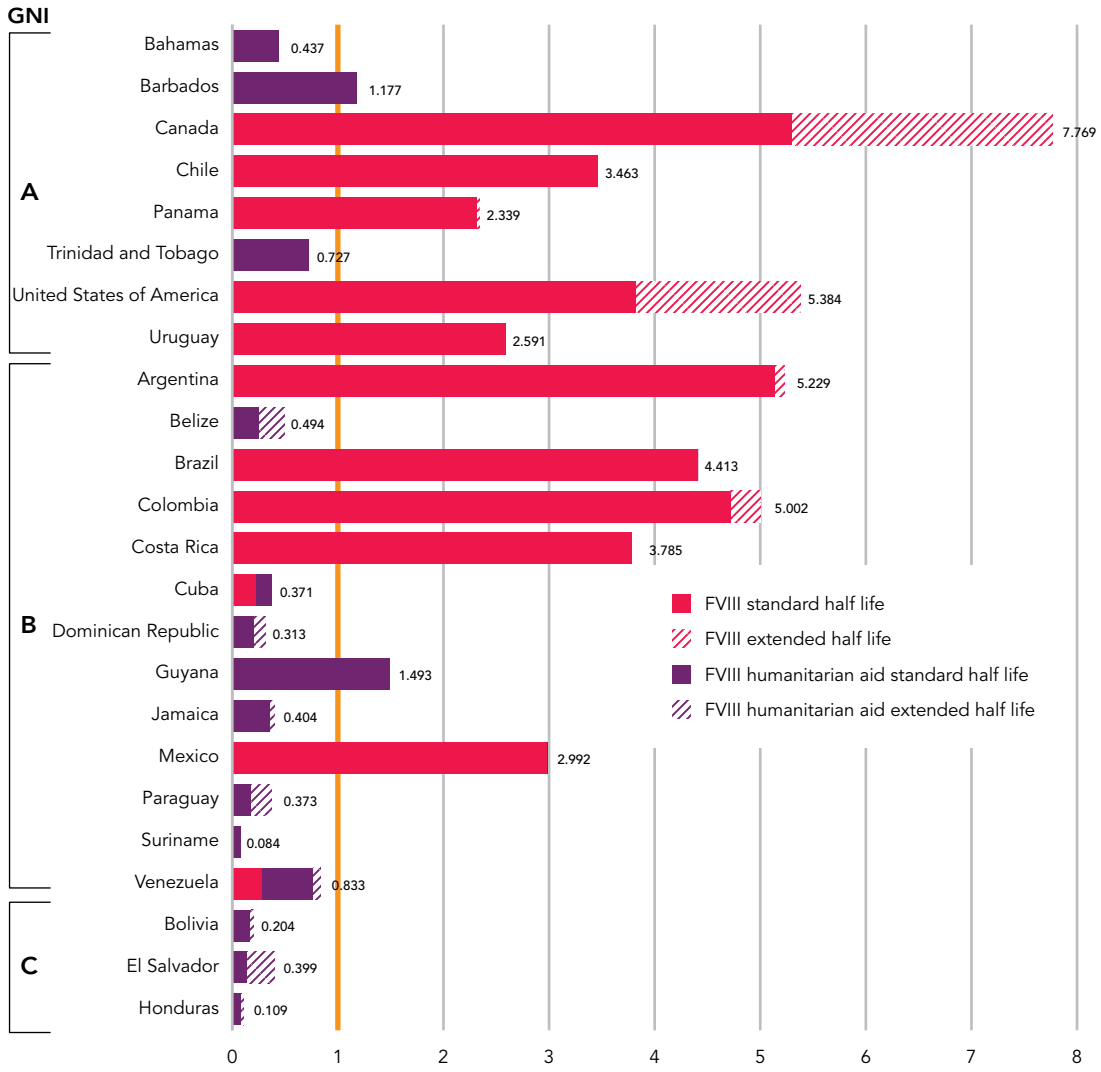
FIGURE G1b. **Mean per capita factor IX use in 2021 – regional and GNI comparisons of IU/total population: Africa**



Economic category based on The World Bank Group 2021 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,085; C lower middle income, $1,086-$4,255; B upper middle income, $4,256-$13,205; and A high income, $13,205 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 2021 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.

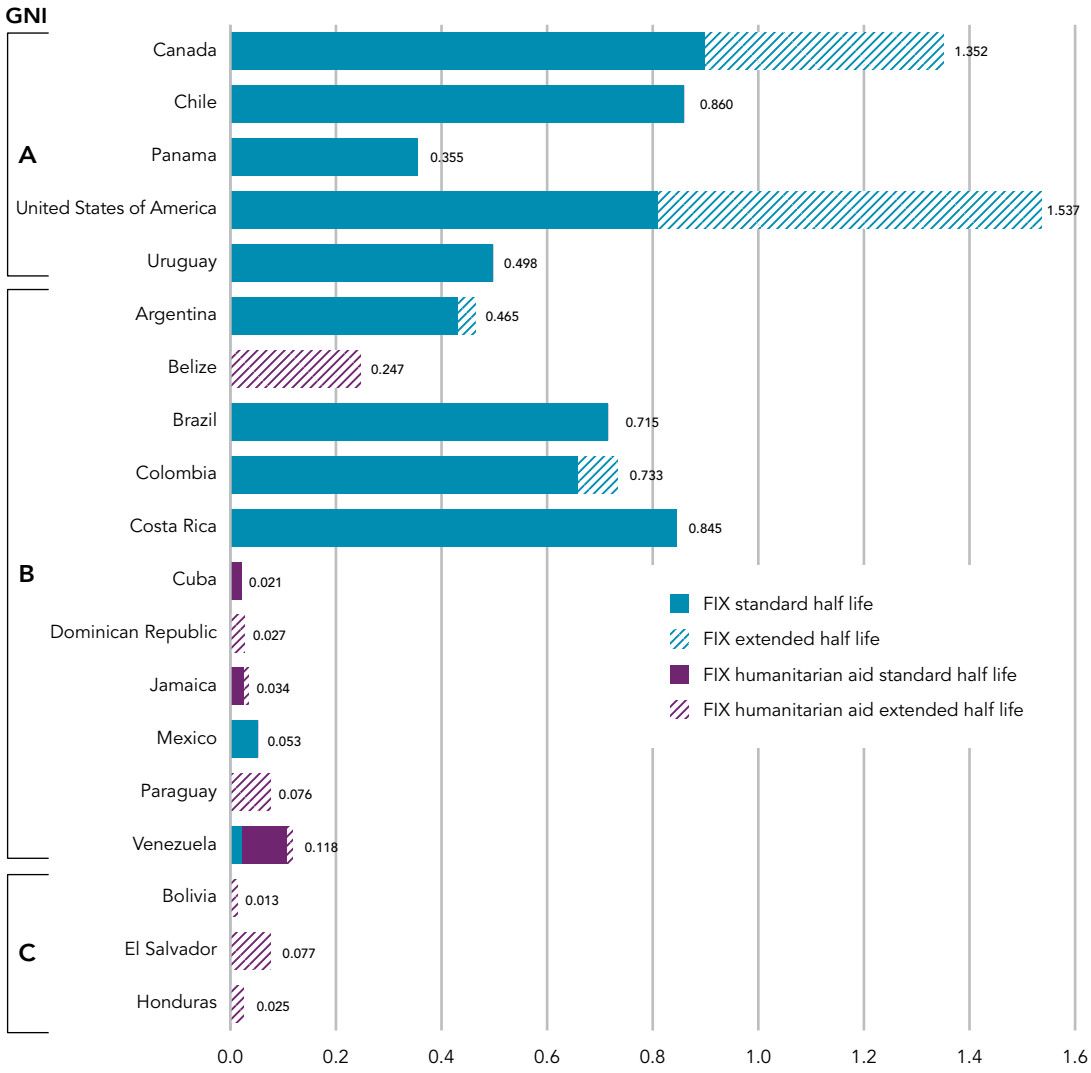
FIGURE G2a. **Mean per capita factor VIII use in 2021 – regional and GNI comparisons of IU/total population: Americas**



Economic category based on The World Bank Group 2021 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,085; C lower middle income, $1,086-$4,255; B upper middle income, $4,256-$13,205; and A high income, $13,205 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 2021 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.

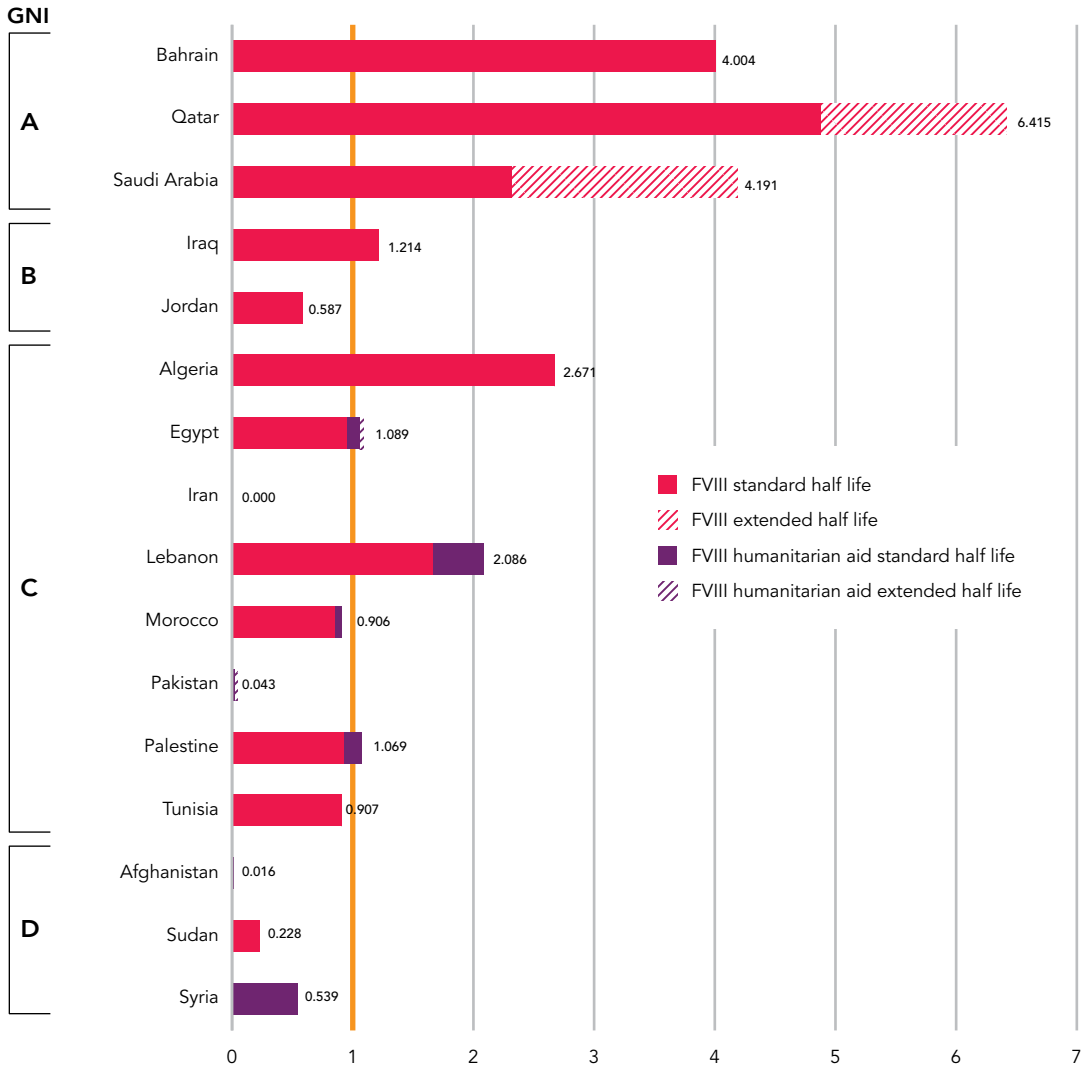
FIGURE G2b. **Mean per capita factor IX use in 2021 – regional and GNI comparisons of IU/total population: Americas**



Economic category based on The World Bank Group 2021 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,085; C lower middle income, $1,086-$4,255; B upper middle income, $4,256-$13,205; and A high income, $13,205 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 2021 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.

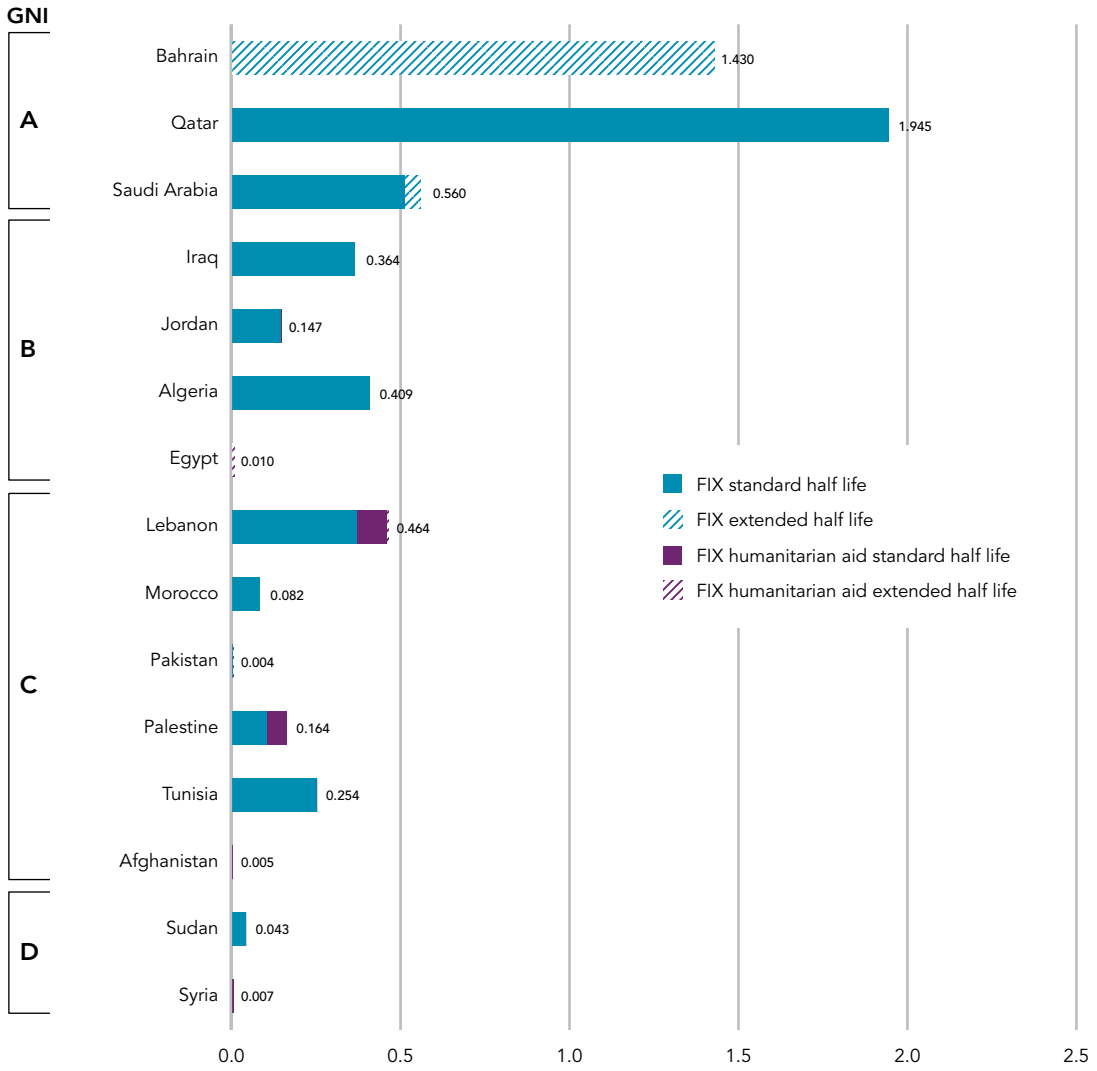
FIGURE G3a. **Mean per capita factor VIII use in 2021 – regional and GNI comparisons of IU/total population: Eastern Mediterranean**



Economic category based on The World Bank Group 2021 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,085; C lower middle income, $1,086-$4,255; B upper middle income, $4,256-$13,205; and A high income, $13,205 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 2021 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.

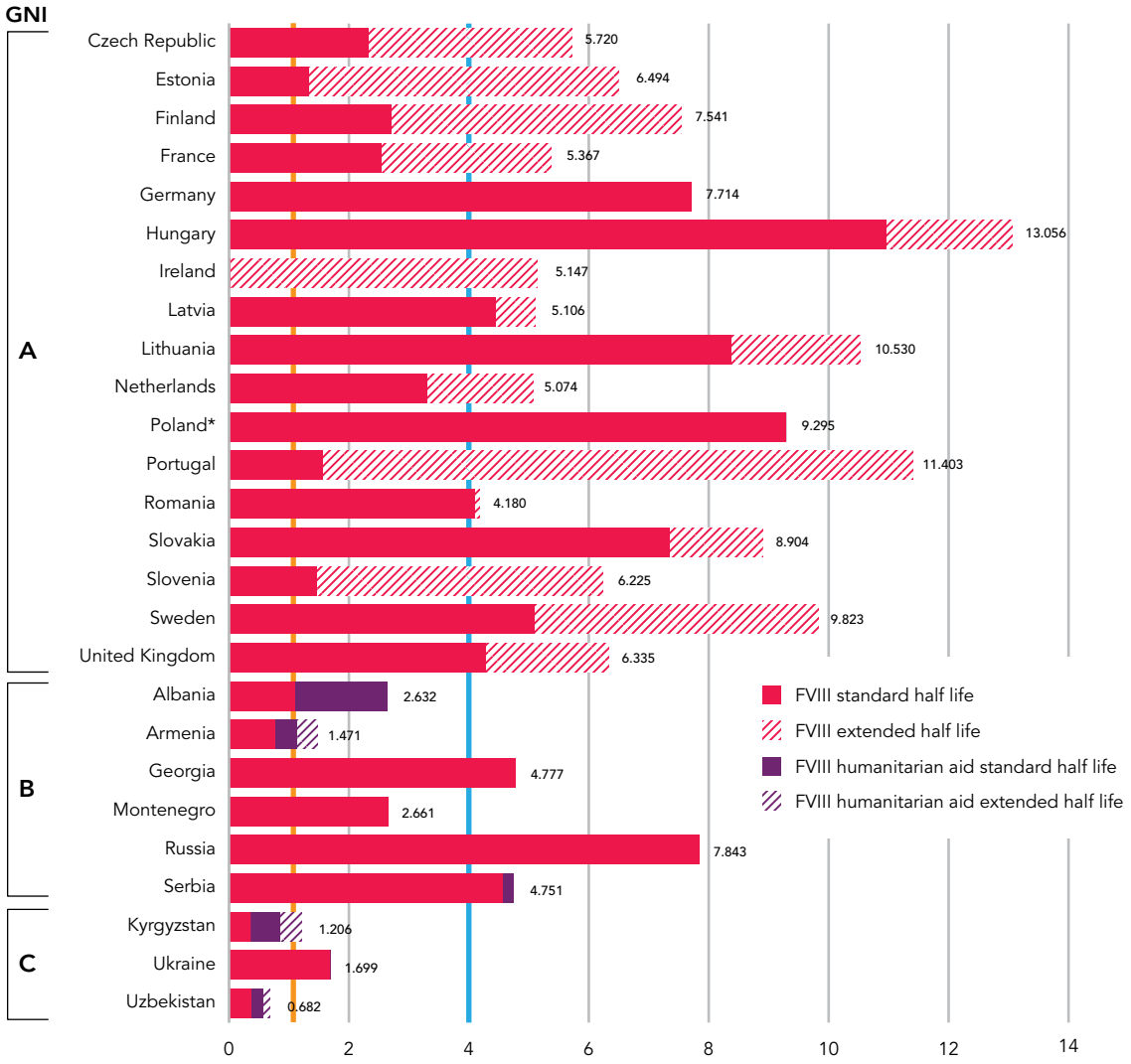
FIGURE G3b. **Mean per capita factor IX use in 2021 – regional and GNI comparisons of IU/total population: Eastern Mediterranean**



Economic category based on The World Bank Group 2021 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,085; C lower middle income, $1,086-$4,255; B upper middle income, $4,256-$13,205; and A high income, $13,205 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 2021 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 2021 – regional and GNI comparisons of IU/total population: Europe**

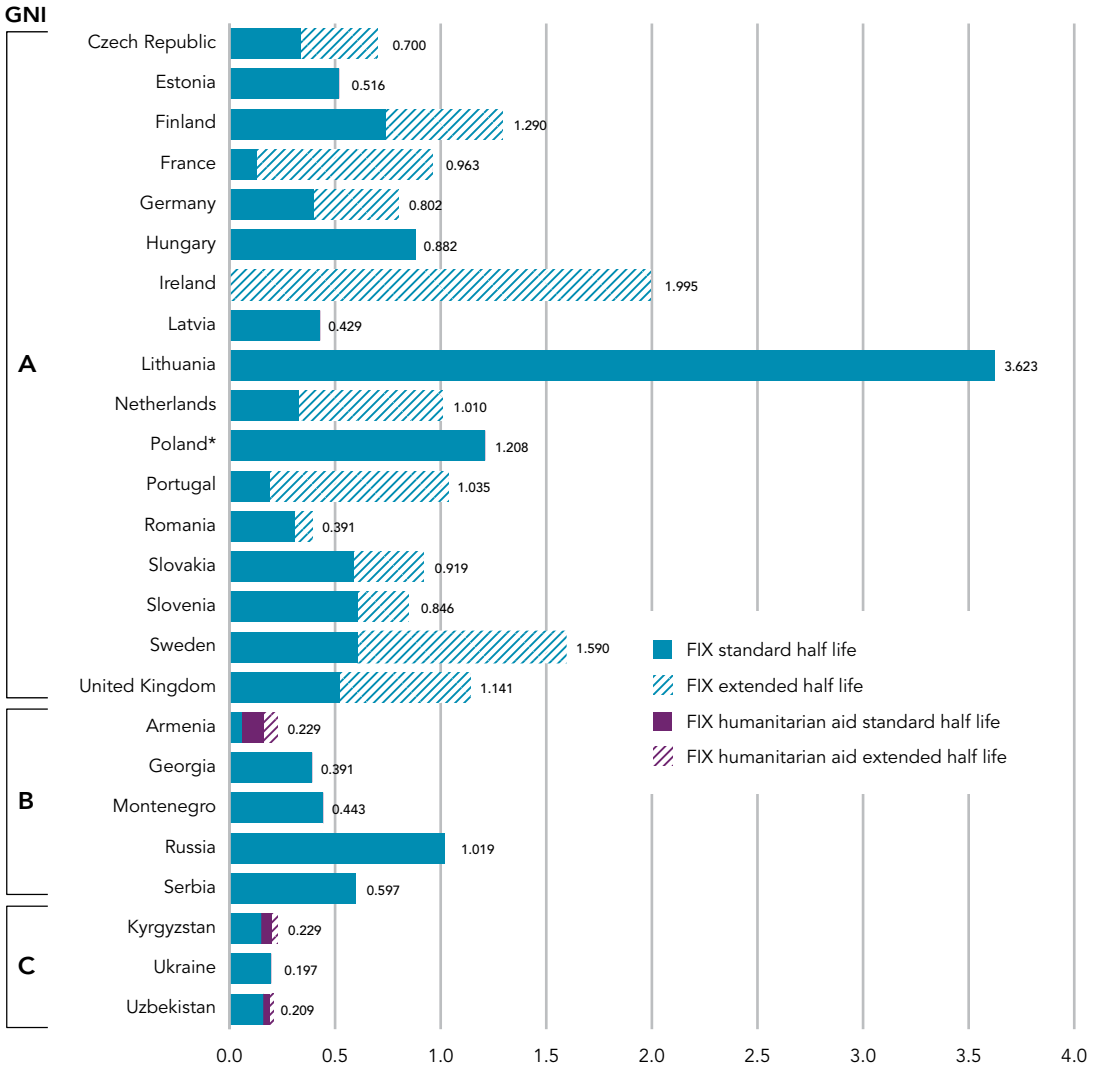


Economic category based on The World Bank Group 2021 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,085; C lower middle income, $1,086-$4,255; B upper middle income, $4,256-$13,205; and A high income, $13,205 or more.

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 2021 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 2021 – regional and GNI comparisons of IU/total population: Europe**

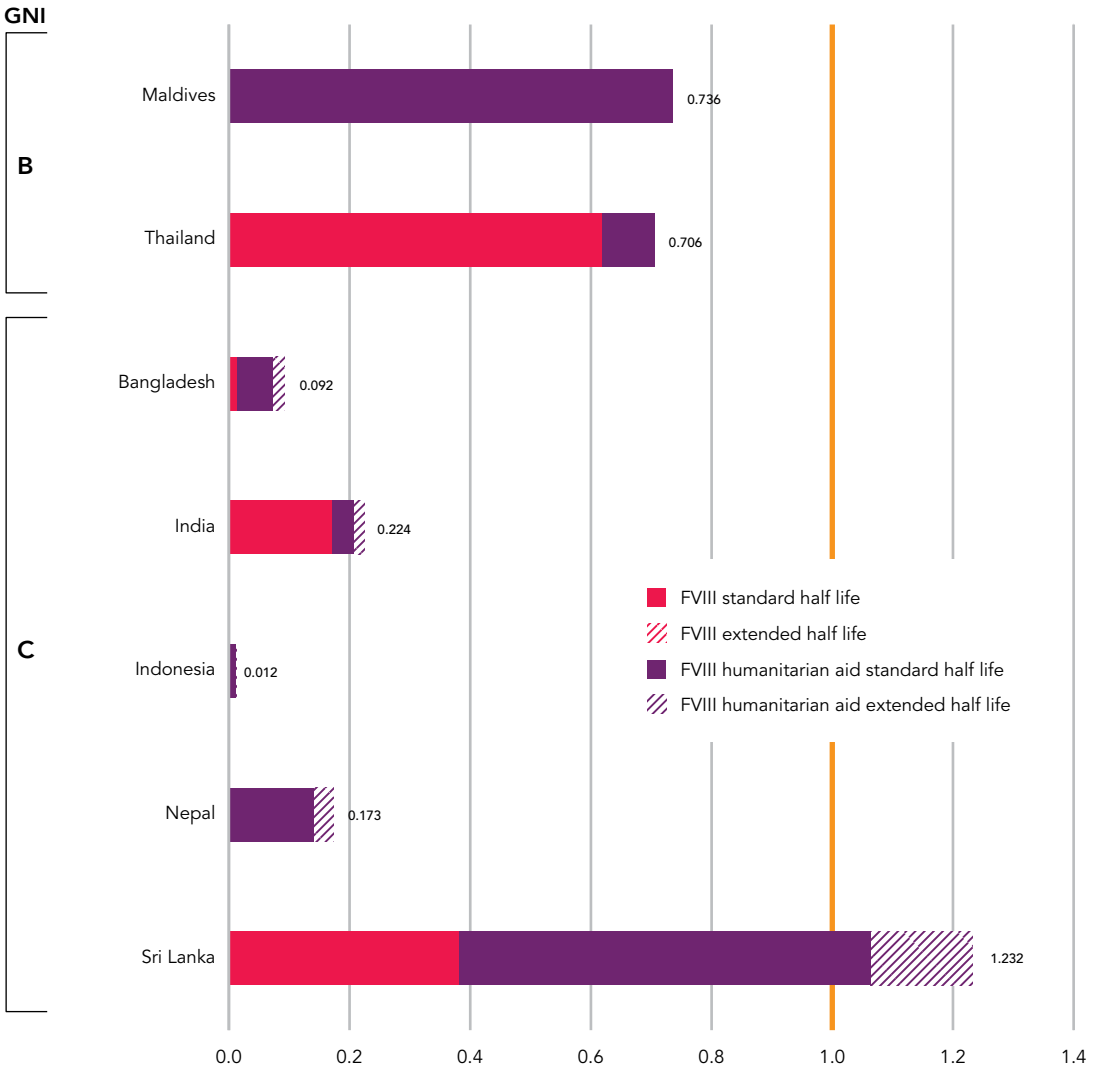


Economic category based on The World Bank Group 2021 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,085; C lower middle income, $1,086-$4,255; B upper middle income, $4,256-$13,205; and A high income, $13,205 or more.

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 2021 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.*

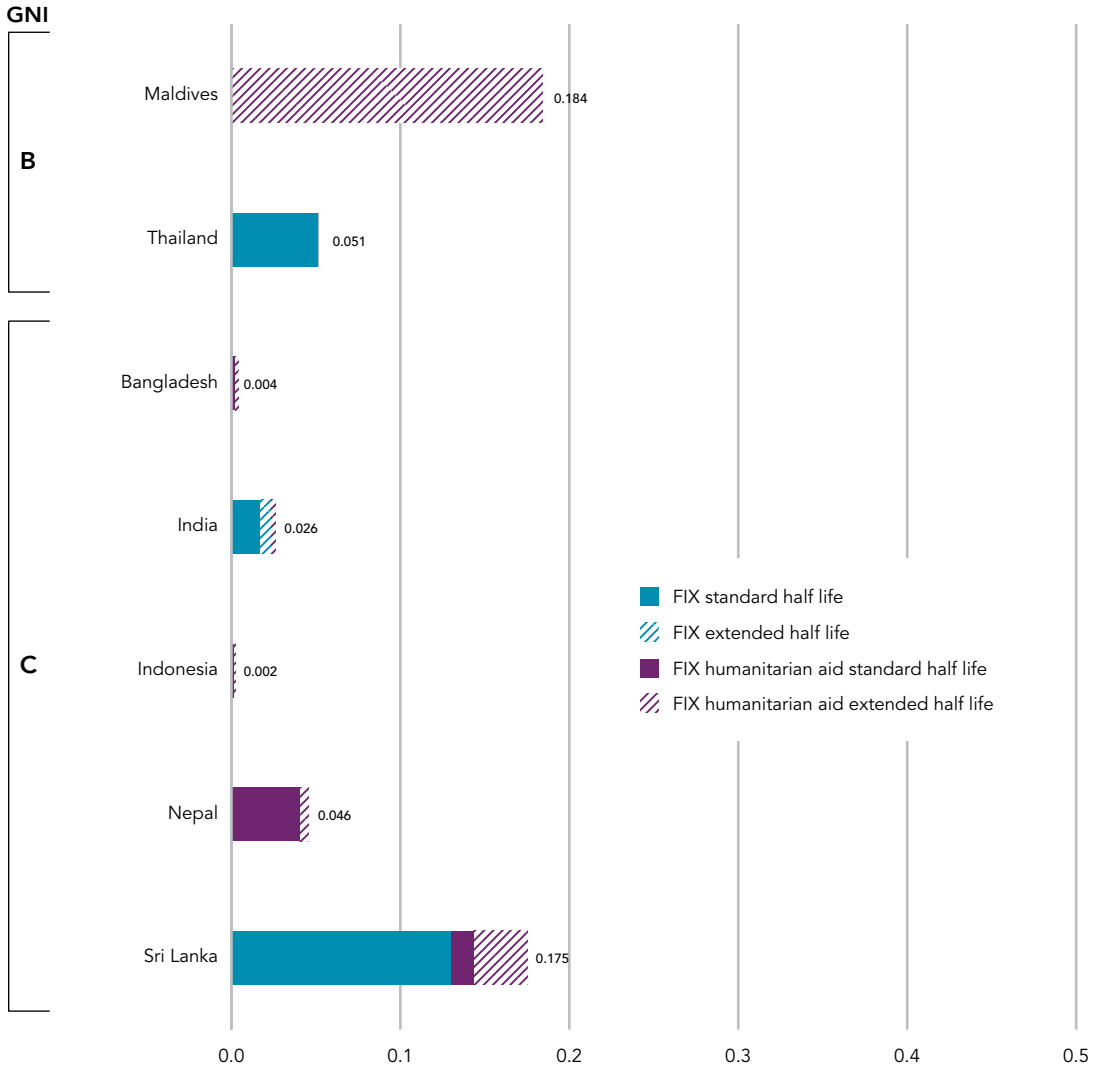
FIGURE G5a. **Mean per capita factor VIII use in 2021 – regional and GNI comparisons of IU/total population: South-East Asia**



Economic category based on The World Bank Group 2021 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,085; C lower middle income, $1,086-$4,255; B upper middle income, $4,256-$13,205; and A high income, $13,205 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 2021 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.

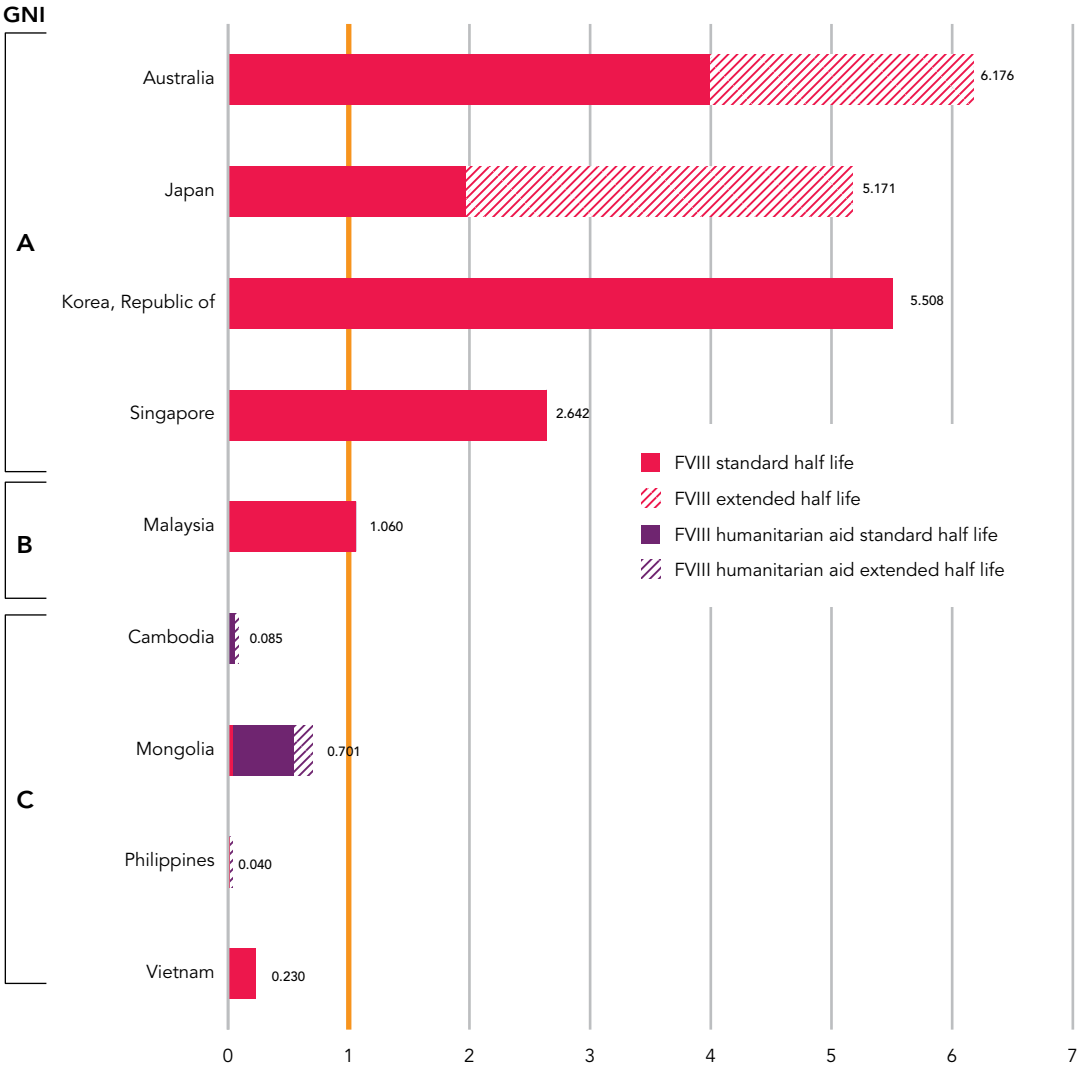
FIGURE G5b. **Mean per capita factor IX use in 2021 – regional and GNI comparisons of IU/total population: South-East Asia**



Economic category based on The World Bank Group 2021 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,085; C lower middle income, $1,086-$4,255; B upper middle income, $4,256-$13,205; and A high income, $13,205 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 2021 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.

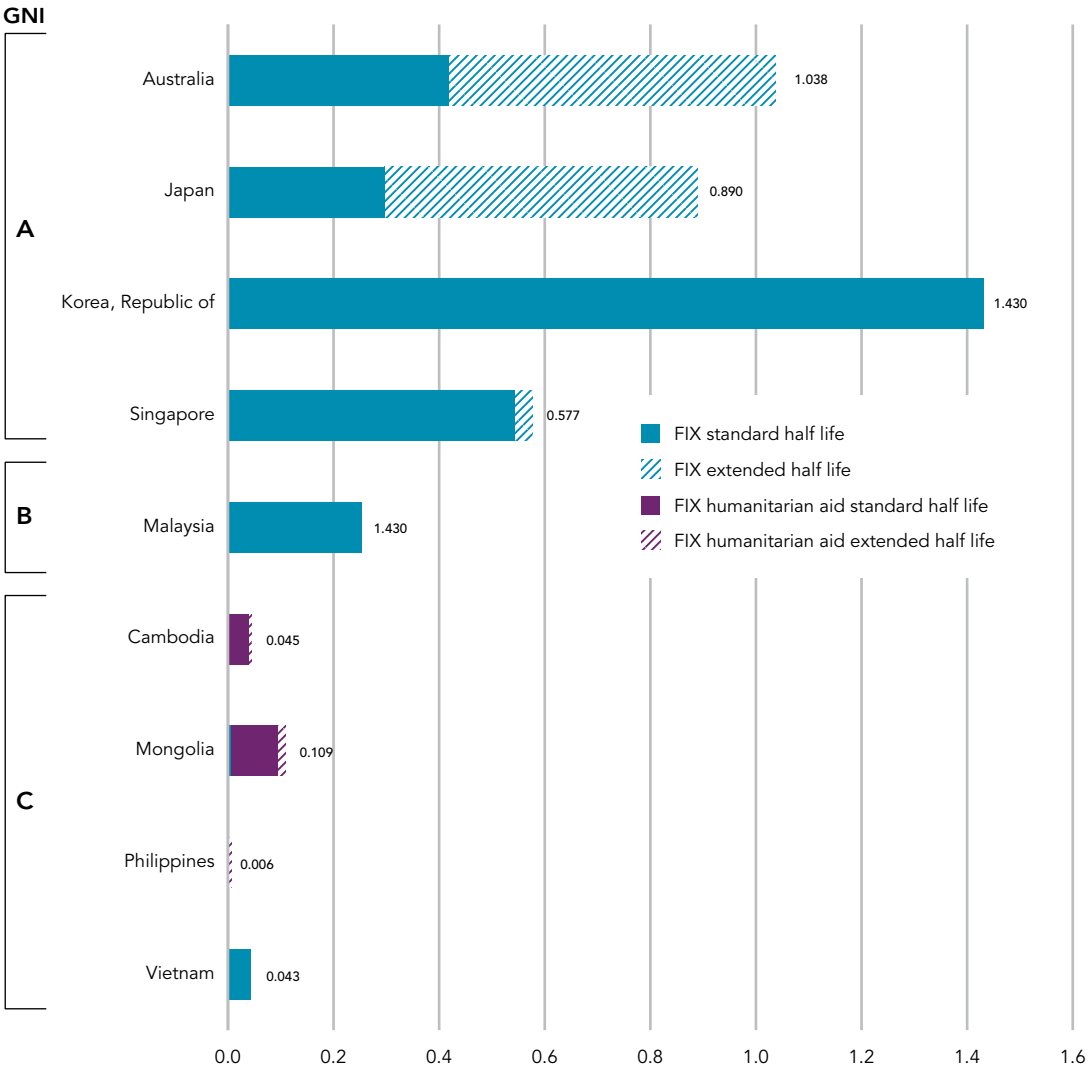
FIGURE G6a. **Mean per capita factor VIII use in 2021 – regional and GNI comparisons of IU/total population: Western Pacific**



Economic category based on The World Bank Group 2021 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,085; C lower middle income, $1,086-$4,255; B upper middle income, $4,256-$13,205; and A high income, $13,205 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 2021 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 2021 – regional and GNI comparisons of IU/total population: Western Pacific**



Economic category based on The World Bank Group 2021 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,085; C lower middle income, $1,086-$4,255; B upper middle income, $4,256-$13,205; and A high income, $13,205 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 2021 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**

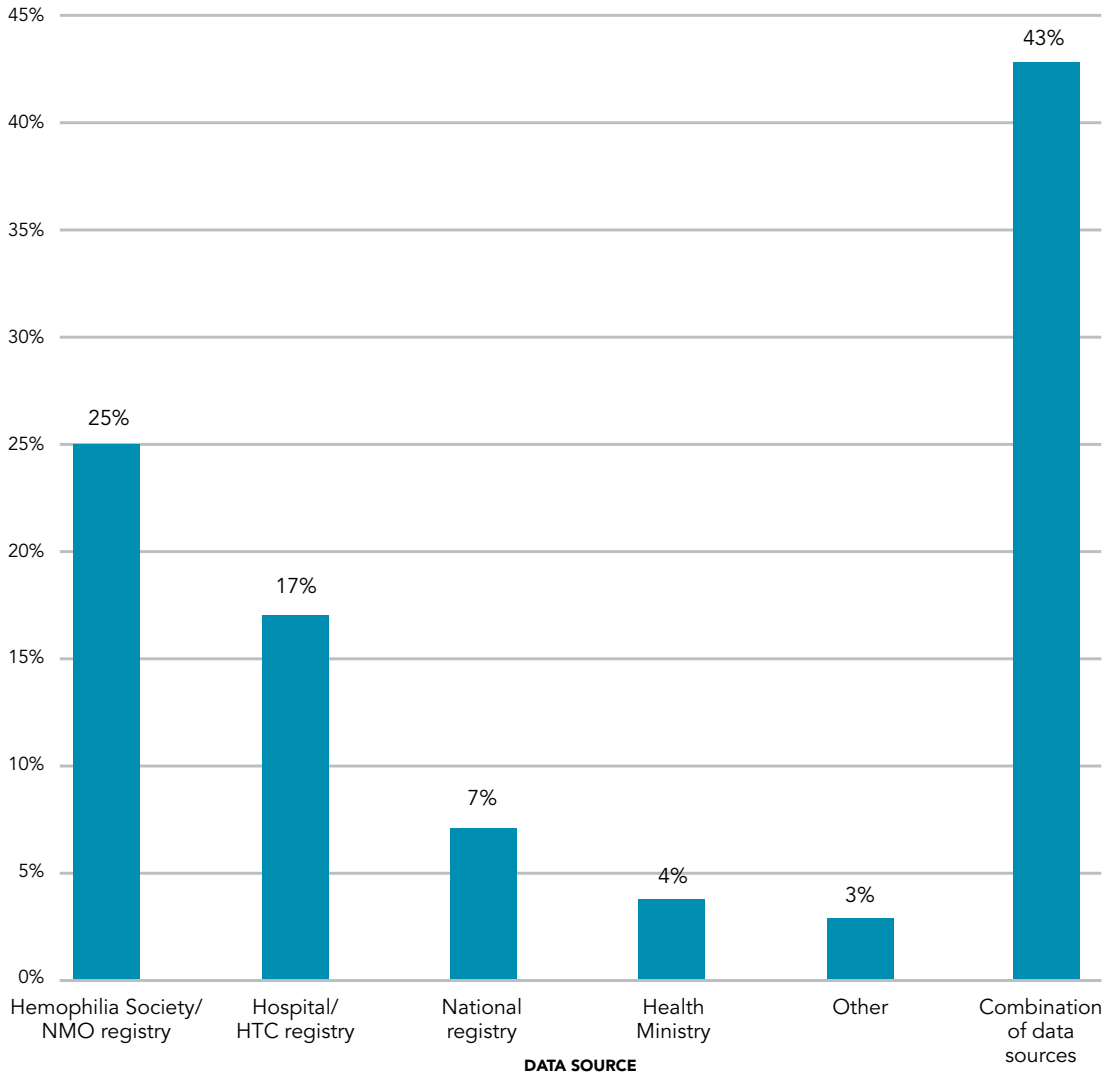
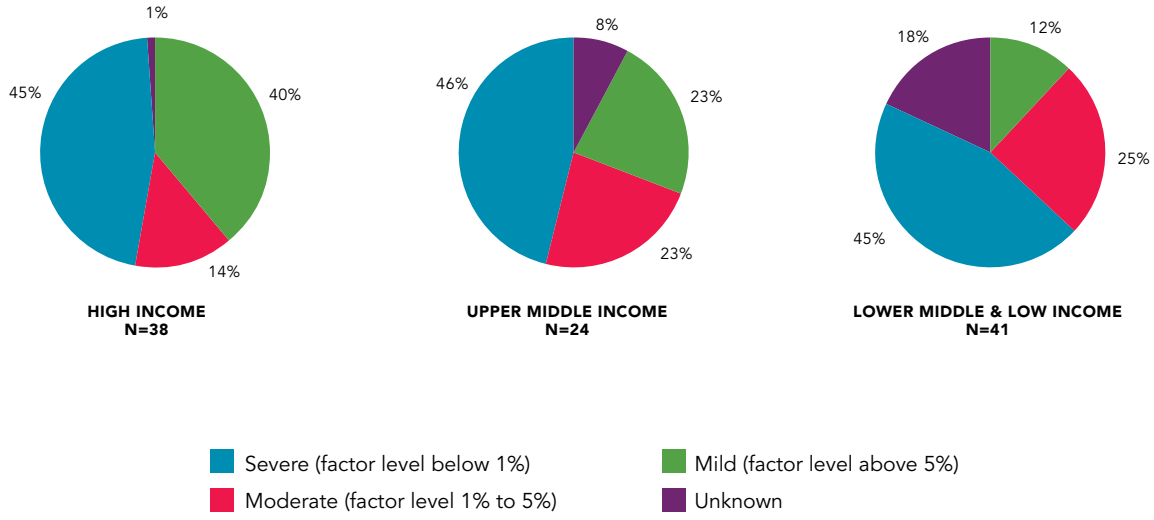


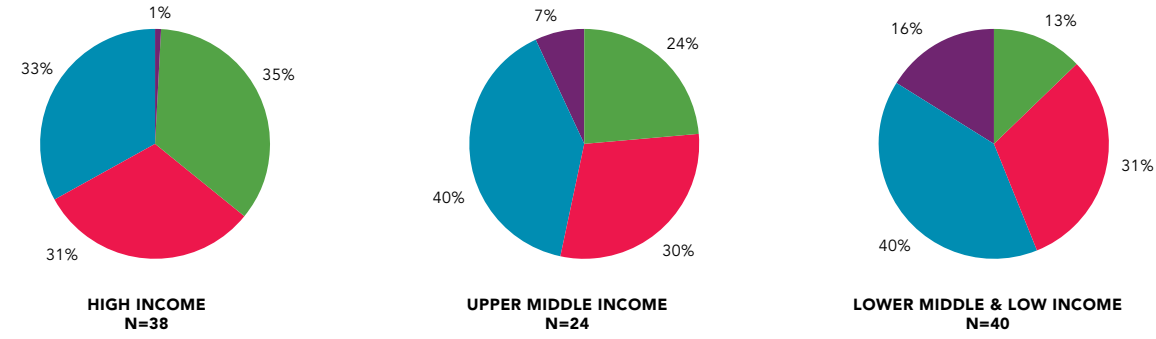
FIGURE I1. **Severity of hemophilia in males by GNI**

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

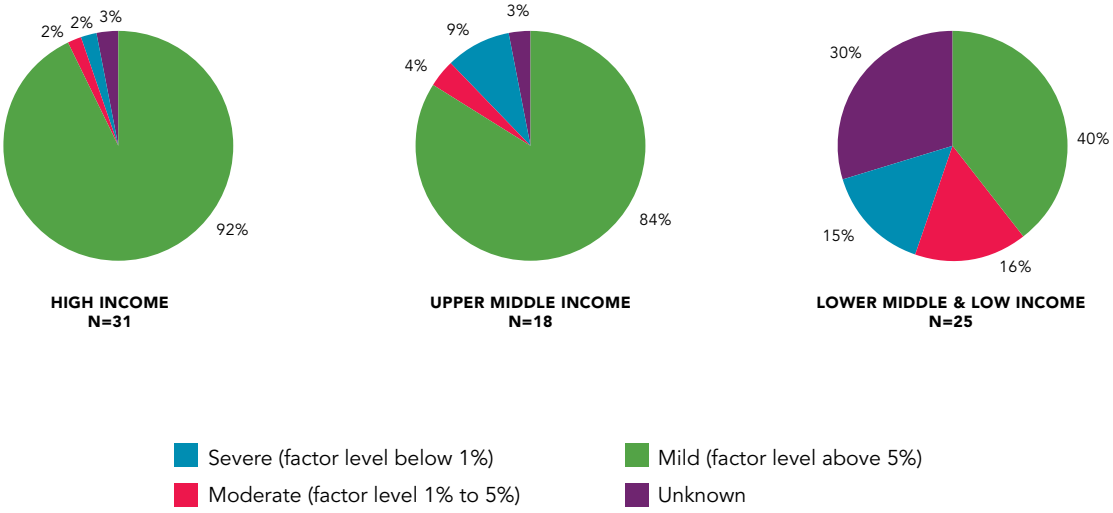


Economic category based on The World Bank Group 2021 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,085; C lower middle income, $1,086-$4,255; B upper middle income, $4,256-$13,205; and A high income, $13,205 or more.

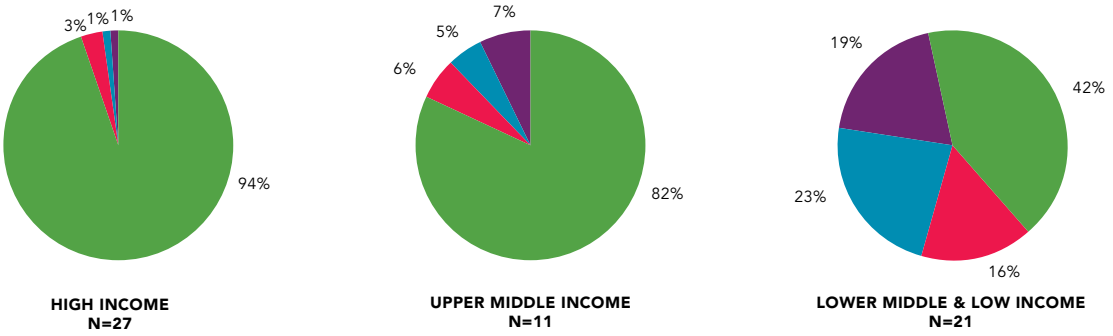
FIGURE I2. **Severity of hemophilia in females–by GNI**

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 2021 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". GNI in US dollars: D low income, $0–$1,085; C lower middle income, $1,086-$4,255; B upper middle income, $4,256-$13,205; and A high income, $13,205 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	39,835,428	610	7	Not Known
Albania	2,811,666	247	8	11
Algeria	44,616,626	2,634	526	841
Angola	33,933,611	89	Not Known	1
Argentina	45,808,747	2,843	399	11
Armenia	2,968,128	238	16	95
Australia	25,739,256	2,910	2,460	1,064
Austria	8,956,279	856	Not Known	Not Known
Bahamas	396,914	9	2	0
Bahrain	1,748,295	100	300	79
Bangladesh	166,303,494	2,490	5	5
Barbados	287,708	27	3	3
Belgium	11,587,882	1,328	2,274	642
Belize	404,915	19	Not Known	Not Known
Benin	12,451,031	129	7	2
Bolivia	11,832,936	150	3	Not Known
Botswana	2,397,240	55	7	Not Known
Brazil	213,993,441	13,337	10,231	3,959
Burkina Faso	21,497,097	126	Not Known	Not Known
Cambodia	16,946,446	268	7	200
Cameroon	27,224,262	226	6	0
Canada	38,246,108	4,050	4,901	2,638
Chile	19,212,362	1,909	731	923
China	1,412,360,000	21,561	Not Known	Not Known
Colombia	51,265,841	3,931	3,654	808
Congo, Republic of the	92,377,986	36	Not Known	Not Known
Costa Rica	5,139,053	227	94	86
Côte d'Ivoire	27,053,629	133	3	6
Croatia	3,899,000	346	181	Not Known

Country	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Cuba	11,317,498	498	485	3,707
Czech Republic	10,703,446	1,051	803	164
Dominican Republic	10,953,714	526	52	59
Egypt	104,258,327	6,505	650	1,477
El Salvador	6,518,500	203	2	0
Eritrea	3,646,413	75	Not Known	Not Known
Estonia	1,329,254	124	129	127
Ethiopia	117,876,226	367	22	Not Known
Finland	5,541,696	310	569	Not Known
France	67,499,343	9,464	3,306	1,388
Georgia	3,708,610	346	64	65
Germany	83,129,285	4,548	5,364	2,906
Ghana	31,732,128	451	11	Not Known
Guyana	790,329	24	0	Not Known
Honduras	10,062,994	385	21	3
Hong Kong	7,413,100	151	4	5
Hungary	9,709,886	1,135	1,452	739
India	1,393,409,033	25,384	927	593
Indonesia	276,361,788	2,939	20	Not Known
Iran	85,028,760	10,605	1,832	3,945
Iraq	41,179,351	2,567	704	577
Ireland	5,028,230	908	1,859	1,546
Israel	9,364,000	748	200	733
Jamaica	2,973,462	91	3	11
Japan	125,681,593	6,909	1,490	471
Jordan	10,269,022	494	262	279
Kenya	54,985,702	774	39	16
Korea, Republic of	51,744,876	2,264	165	176
Kuwait	4,328,553	120	30	14
Kyrgyzstan	6,694,200	411	20	9
Latvia	1,883,162	122	90	21
Lebanon	6,769,151	245	183	78
Lesotho	2,159,067	31	Not Known	2
Lithuania	2,795,321	193	310	18
Luxembourg	639,070	20	1	Not Known
Madagascar	28,427,333	145	2	13

Country	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Malawi	19,647,681	95	Not Known	Not Known
Malaysia	32,776,195	1,140	133	99
Maldives	543,620	19	Not Known	Not Known
Mali	20,855,724	165	17	38
Malta	516,869	37	46	0
Mauritius	1,266,060	93	1	9
Mexico	130,262,220	5,892	367	65
Mongolia	3,329,282	121	18	Not Known
Montenegro	620,173	46	3	4
Morocco	37,344,787	1,229	196	163
Nepal	29,674,920	718	10	36
Netherlands	17,533,405	1,574	583	147
New Zealand	5,122,600	738	625	683
Nigeria	211,400,704	695	13	Not Known
Norway	5,408,320	453	467	80
Pakistan	225,199,929	2,801	491	212
Palestine	4,922,749	352	60	138
Panama	4,381,583	319	537	113
Paraguay	7,219,641	436	4	5
Philippines	111,046,910	1,632	50	Not Known
Poland	37,781,024	3,227	2,803	1,138
Portugal	10,299,423	1,006	984	971
Qatar	2,930,524	63	47	17
Romania	19,115,146	1,825	325	13
Russia	143,446,060	8,141	2,738	Not Known
Saudi Arabia	35,340,680	1,135	432	719
Senegal	17,196,308	323	14	20
Serbia	6,844,078	565	322	79
Singapore	5,453,566	370	Not Known	78
Slovakia	5,447,247	706	776	1,687
Slovenia	2,107,007	268	207	76
South Africa	60,041,996	2,419	671	232
Spain	47,326,687	4,186	720	120
Sri Lanka	22,156,000	1,187	72	59
Sudan	44,909,351	1,393	410	480
Suriname	591,798	16	3	0

Country	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Sweden	10,415,811	1,033	962	Not Known
Syria	18,275,704	1,079	151	234
Tanzania	61,498,438	183	5	3
Thailand	69,950,844	1,936	163	91
Togo	8,478,242	47	Not Known	Not Known
Trinidad and Tobago	1,403,374	68	10	2
Tunisia	11,935,764	613	253	359
Uganda	47,123,533	319	2	Not Known
Ukraine	43,814,581	4,376	469	Not Known
United Kingdom	67,326,569	8,671	11,341	12,884
United States of America	331,893,745	18,398	13,535	10,173
Uruguay	3,485,152	281	263	21
Uzbekistan	34,915,100	1,779	257	83
Venezuela	28,704,947	2,905	1,199	1,102
Vietnam	98,168,829	4,078	192	592
Zambia	18,920,657	211	5	0
Zimbabwe	15,092,171	198	Not Known	0

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 Unknown	VWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXIII	Bleeding Disorder: type unknown	Glanzmann's thrombasthenia	Bernard-Soulier syndrome	Platelet disorders: other/ unknown
Afghanistan	535	68	7	7												
Albania	210	37		8					5	2		2		1		1
Algeria	2,079	555		526	64	10	84	31	499	36	21	19	32	30	15	
Angola	77	12							1							
Argentina	2,448	392	3	399	0	0	0	2	2	0	1	1	0	2	0	3
Armenia	211	27	0	16	2	0	4	3	45	2	10	1	12	4	7	5
Australia	2,361	549	0	2,460	149	0	22	0	109	20	354	30	0	31	15	334
Austria	708	148	0													
Bahamas	7	1	1	2	0	0	0	0	0	0	0	0	0	0	0	0
Bahrain	90	10	0	300	0	10	10	6	8	11	2	8	0	20	4	0
Bangladesh	2,071	413	6	5	2		2					1				
Barbados	16	11		3			2	1								
Belgium	1,070	250	8	2,274	2	2	24	0	183	13	157	5	32	21	9	194
Belize	14	5														
Benin	107	4	18	7					2							
Bolivia	122	28	0	3												
Botswana	47	8	0	7												
Brazil	11,141	2,196		10,231	63	20	281	53	1,809	168	370	90		421	115	569
Burkina Faso	97	29	0													
Cambodia	226	42	0	7								1				199
Cameroon	188	35	3	6												
Canada	3,323	727	0	4,901	199	19	93	0	598	60	586	65	0	71	39	908
Chile	1,670	186	53	731	0	0	18	7	405	20	49	7	3	8	4	402
China	17,779	3,782														
Colombia	3,220	711	0	3,654	88	15	87	55	232	40	139	88	0	16	2	46
Congo, Republic of the	25	11														
Costa Rica	182	43	2	94	4	0	2	13	46	12	7	2				
Côte d'Ivoire	115	18	0	3	0	0	0	0	3	3	0	0	0	0	0	0
Croatia	277	69	0	181												
Cuba	414	84	0	485	3	1	2	0	2	0	12	7	19	2	0	3,659
Czech Republic	908	143	0	803	0	4	14	0	91	6	29	1	19			

Country	Hemophilia A	Hemophilia B	Hemophilia Unknown	VWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXIII	Bleeding Disorder: type unknown	Glanzmann's thrombasthenia	Bernard-Soulier syndrome	Platelet disorders: other/ unknown
Dominican Republic	470	42	14	52	0	0	0	0	12	40	0	5	0	2	0	0
Egypt	5,295	1,210		650	215	9	183	6	255	117	82	50	25	477	58	
El Salvador	180	23		2	0	0	0	0	0	0	0	0	0	0	0	0
Eritrea	68	7														
Estonia	113	11		129	12	1	6	1	37	3	8		38		2	19
Ethiopia	172	32	163	22												
Finland	180	34	96	569												
France	7,623	1,841	0	3,306	47	1	63	26	233	35	273	37	0	253	70	350
Georgia	289	57		64	1		1		46	1		3		7		6
Germany	3,793	755	0	5,364	545	64	205		1,219	140	115	618				
Ghana	366	28	57	11												
Guyana	23	1	0	0												
Honduras	324	36	25	21								3				
Hong Kong	126	23	2	4					3	2						
Hungary	892	243	0	1,452	21	2	26	0	405	25	97	5	79	3	1	75
India	21,350	3,475	559	927	55	10	51	8	99	67	40	149		93		21
Indonesia	2,425	378	136	20												
Iran	5,498	1,162	3,945	1,832	175	31	289	262	988	241	317	294	269	637	108	334
Iraq	2,024	543		704	60	2	15	4	152	30	14	65		125	33	77
Ireland	685	223	0	1,859	107	3	195	1	317	182	293	15	0	14	4	415
Israel	638	110		200	5	0	9	15	92	9	380	8		45	5	165
Jamaica	79	12		3						5	3			1		2
Japan	5,657	1,252		1,490	106	8	57	9	124	28	54	85				
Jordan	358	110	26	262	4	4	15	0	62	25	40	17	0	112	0	0
Kenya	623	151	0	39	0	0	0	0	3	1	0	0	0	0	0	12
Korea, Republic of	1,778	446	40	165	10	0	7	0	54	2	32	4	67	0	0	0
Kuwait	100	20		30		1			3	1	1	8				
Kyrgyzstan	330	80	1	20	3	1								5		
Latvia	99	23	0	90	0	0	2	2	12	3	0	0		1	1	
Lebanon	191	54	0	183	35	0	9	1	10	7	5	4	0	1	1	5
Lesotho	29	2									2					
Lithuania	165	27	1	310					13	2						3
Luxembourg	16	4	0	1												
Madagascar	81	64	0	2	13	0	0	0	0	0	0	0	0	0	0	0
Malawi	27	5	63													
Malaysia	974	166	0	133	2	2	2	0	30	14	11	9	0	21	1	7

Country	Hemophilia A	Hemophilia B	Hemophilia Unknown	VWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXIII	Bleeding Disorder: type unknown	Glanzmann's thrombasthenia	Bernard-Soulier syndrome	Platelet disorders: other/ unknown
Maldives	15	4														
Mali	148	17	0	17	2	0	0	0	0	0	0	1	29	0	0	6
Malta			37	46												
Mauritius	84	9	0	1	0	0	0	0	4	1	0	0	2	2	0	0
Mexico	4,867	728	297	367	3	2	3		30	6	6	4	2	5	0	4
Mongolia	89	32		18												
Montenegro	42	4	0	3	0	0	0	0	1	0	0	3	0	0	0	0
Morocco	1,077	151	1	196	16	10	11	8	65	6	3	2	0	32	3	7
Nepal	608	110		10			2	1	7	23		3				
Netherlands	1,376	198	0	583	12	5	8	1	28	3	22	14		17	1	36
New Zealand	597	141	0	625	28	1	12	0	25	4	21	9	3	8	1	571
Nigeria	645	27	23	13												
Norway	349	104		467	3	2	4		38	5	2	5		15	6	
Pakistan	2,385	416	0	491	21	4	20	8	48	32	1	46	1	27	3	1
Palestine	292	60		60		7	4	1	2	16		2	96	10		
Panama	284	35	0	537	0	0	0	0	12	16	0	0	0	11	1	73
Paraguay	397	39		4					3	2						
Philippines	1,207	214	211	50												
Poland	2,750	477	0	2,803	166	1	37	6	408	32	102	15	2	33	9	327
Portugal	793	213	0	984	37	2	25	5	346	20	160	10	29	34	33	270
Qatar	53	10	0	47	0	0	1	0	3	1	0	2	0	2	5	3
Romania	1,615	210		325	2			1	5		2		3			
Russia	6,867	1,274		2,738												
Saudi Arabia	920	208	7	432	13	22	48	6	77	50	21	117	4	283	30	48
Senegal	282	41	0	14	1	0	1	0	4	1	0	1	0	2	0	10
Serbia	476	89	0	322	10	0	4	2	42	1	12	5	1	0	2	0
Singapore	224	47	99				13		9	1	50	5				
Slovakia	613	93	0	776	432	0	89	1	990	39	65	11	0	10	15	35
Slovenia	235	33	0	207	4	0	13	3	21	4	24	0	0	7	0	
South Africa	2,021	398	0	671	0	1	47	5	18	11	27	8	0	26	31	58
Spain	1,822	282	2,082	720	20	3	11		30	8	30	17		1		
Sri Lanka	956	231		72	1	2	11	1	3	2	10	9		11		9
Sudan	1,120	273		410	58	1	64	4	55	30	8	28		20	17	195
Suriname	14	2	0	3	0	0	0	0	0	0	0	0	0	0	0	0
Sweden	815	216	2	962												
Syria	976	103	0	151	31	0	18	34	47	4	0	2	1	55	11	31
Tanzania	135	22	26	5						3						

Country	Hemophilia A	Hemophilia B	Hemophilia Unknown	VWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXIII	Bleeding Disorder: type unknown	Glanzmann's thrombasthenia	Bernard-Soulier syndrome	Platelet disorders: other/ unknown
Thailand	1,710	226		163	1	1	9	2	29	2	3	3		13	11	17
Togo	35	2	10													
Trinidad and Tobago	55	13	0	10			1			1						
Tunisia	479	134	0	253	36	1	22	10	99	7	58	32	4	69	8	13
Uganda	272	44	3	2												
Ukraine	1,860	328	2,188	469												
United Kingdom	7,064	1,607	0	11,341	1,013	18	273	30	2,022	338	3,906	84	1,510	145	102	3,443
United States of America	14,098	4,300		13,535	279	45	131	14	1,266	166	657	138	2,696	170	44	4,567
Uruguay	235	38	8	263			1		6		9			1	4	
Uzbekistan	1,580	189	10	257	11	2	4		23	7	14			19	3	
Venezuela	2,289	616		1,199	21	65	41	29	172	111	399	15	18	28	6	197
Vietnam	3,379	699	0	192	26	9	22	16	85	28	35	29	3	117	3	219
Zambia	163	34	14	5	0	0	0	0	0	0	0	0	0	0	0	0
Zimbabwe	171	13	14													

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	Male	Percent male	Female	Percent female	Sex not known	Percent not known
Hemophilia A	**117**	185,318	150,018	**81%**	6,276	**3%**	9,027	**5%**
Hemophilia B	**117**	37,998	29,949	**79%**	2,103	**6%**	1,726	**5%**
Hemophilia Unknown	**86**	10,261	3,727	**36%**	2,127	**21%**	74	**1%**
von Willebrand disease	**105**	89,848	29,968	**33%**	50,660	**56%**	8,029	**9%**
Factor I Deficiency	**71**	4,239	1,623	**38%**	2,082	**49%**	526	**12%**
Factor II Deficiency	**70**	424	177	**42%**	177	**42%**	64	**15%**
Factor V Deficiency	**75**	2,730	1,197	**44%**	1,296	**47%**	203	**7%**
Factor V+VIII Deficiency	**66**	694	373	**54%**	315	**45%**	2	**0%**
Factor VII Deficiency	**80**	14,232	6,378	**45%**	6,603	**46%**	1,142	**8%**
Factor X Deficiency	**79**	2,354	1,137	**48%**	1,054	**45%**	132	**6%**
Factor XI Deficiency	**73**	9,151	3,736	**41%**	4,863	**53%**	116	**1%**
Factor XIII Deficiency	**74**	2,327	989	**43%**	745	**32%**	564	**24%**
Bleeding Disorder: Type Unknown	**54**	4,999	1,809	**36%**	3,155	**63%**	0	**0%**
Platelet disorder: Glanzmann's Thombasthenia	**68**	3,597	1,762	**49%**	1,685	**47%**	14	**0%**
Platelet disorder: Bernard-Soulier Syndrome	**61**	843	350	**42%**	429	**51%**	53	**6%**
Platelet Disorders: Other/ Unknown	**61**	17,951	5,927	**33%**	11,248	**63%**	213	**1%**

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.

Country	Hemophilia A active inhibitors	Hemophilia A new cases inhibitors	Hemophilia B active inhibitors	Hemophilia B new cases inhibitors
Albania	18		2	
Algeria	135	13	0	0
Argentina	66	4	7	0
Armenia	15	5	3	2
Australia	71	9	4	1
Austria	16		0	
Bahamas	1	0	0	0
Bahrain	4	2	0	0
Bangladesh	9			
Barbados	1	0	1	0
Benin	7	3		
Bolivia	3	0	0	0
Botswana	3	0	0	0
Brazil	388	170	21	16
Burkina Faso	1	0	0	0
Cambodia	9	1	0	0
Cameroon	14	2		
Canada	55	8	1	0
Chile	29	7	2	
Colombia	218	7	23	0
Congo, Republic of the	3	3	0	
Costa Rica	22	1	0	0
Côte d'Ivoire	3	0	1	0
Croatia	14	1	4	0
Cuba	32	1	0	0
Czech Republic	21	3	2	0
Dominican Republic	18		6	
Egypt	573	130	2	0

Country	Hemophilia A active inhibitors	Hemophilia A new cases inhibitors	Hemophilia B active inhibitors	Hemophilia B new cases inhibitors
El Salvador	18			
Eritrea	0	0	0	0
Estonia	4	0		
Finland	13	0	0	0
France	223	9	15	1
Georgia	1			
Germany	105		1	
Ghana	0	0	0	0
Honduras	14	0	0	0
Hong Kong	8		1	
Hungary	27			
India	564		24	
Iran	357	5	36	1
Iraq	205	1	9	1
Ireland	9	0	3	0
Israel	18	2	2	
Jamaica	16		0	
Japan	95		17	
Kenya	14	24	2	5
Korea, Republic of	71		7	
Kyrgyzstan	5			
Lebanon	10	2	1	1
Lesotho	1	1		
Lithuania	8	0	0	0
Luxembourg	0	0	0	0
Madagascar	5	2	1	0
Malaysia	104	6	8	0
Maldives	1	1		
Mali	4	2	0	0
Mauritius	0	0	0	0
Mexico	288		17	
Mongolia	1			
Montenegro	2	0	0	0
Morocco	158	28	5	0
Nepal	21	4		
Netherlands	19			

Country	Hemophilia A active inhibitors	Hemophilia A new cases inhibitors	Hemophilia B active inhibitors	Hemophilia B new cases inhibitors
New Zealand	30	0	0	0
Nigeria	11	11	0	0
Pakistan	20	0	1	0
Palestine	3		0	
Panama	14	2	0	0
Philippines	34	3	1	0
Poland	174		5	
Portugal	36	3	1	
Qatar	3	2	0	0
Saudi Arabia	122	5	2	0
Senegal	13	1	0	0
Serbia	15	0	0	0
Singapore	6	2		
Slovakia	7	0	1	0
Slovenia	4	0	1	0
South Africa	64	2	5	0
Sri Lanka	92	34		
Sudan	6			
Suriname	0	0	0	0
Sweden	29		3	
Syria	72	1	1	0
Tanzania	4	15		
Thailand	104	4	1	0
Togo	1			
Trinidad and Tobago	4	0	2	0
Tunisia	26	3	4	2
Uganda	8	2	0	0
United Kingdom	230	22	15	2
United States of America	817		79	
Uruguay	8		1	
Uzbekistan	29	0	0	0
Venezuela	96	2	1	0
Vietnam	184	23	0	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**

(106 countries reported age data for hemophilia A)

Country	Hemophilia A	0–4	5–13	14–18	19–44	45+	Age not known
Afghanistan	535	6%	34%	20%	35%	5%	0%
Albania	210	1%	12%	7%	52%	28%	0%
Algeria	2,079	3%	14%	15%	53%	15%	0%
Angola	77	13%	56%	13%	17%	1%	0%
Argentina	2,448	2%	13%	9%	46%	28%	2%
Armenia	211	12%	23%	8%	36%	20%	0%
Australia	2,361	5%	14%	8%	38%	35%	0%
Austria	708	6%	10%	8%	44%	32%	0%
Bahamas	7	0%	14%	14%	57%	14%	0%
Bahrain	90	11%	28%	33%	20%	8%	0%
Bangladesh	2,071	16%	33%	18%	31%	3%	0%
Barbados	16	6%	13%	6%	50%	25%	0%
Belgium	1,070	2%	9%	7%	36%	46%	0%
Belize	14		14%		86%		0%
Benin	107	18%	44%	7%	25%	4%	3%
Bolivia	122	10%	44%	8%	31%	7%	0%
Botswana	47	17%	32%	11%	38%	2%	0%
Brazil	11,141	5%	15%	9%	49%	22%	0%
Burkina Faso	97	27%	46%	11%	14%	1%	0%
Cambodia	226	7%	44%	22%	27%	0%	0%
Cameroon	188	19%	44%	31%	4%	2%	0%
Canada	3,323	3%	11%	7%	42%	36%	0%
Chile	1,624	4%	13%	10%	51%	22%	0%
Colombia	3,220	6%	11%	13%	59%	11%	0%
Congo, Republic of the	25	12%	36%	16%	24%	12%	0%
Costa Rica	182	2%	14%	13%	55%	15%	0%
Côte d'Ivoire	115	14%	34%	16%	33%	3%	0%
Croatia	277	3%	9%	8%	45%	35%	0%
Cuba	414	2%	11%	9%	49%	29%	0%
Czech Republic	908	6%	13%	7%	39%	34%	0%
Dominican Republic	470	4%	18%	8%	48%	6%	16%
Egypt	5,295	7%	21%	11%	46%	15%	0%
El Salvador	180	16%	24%	21%	27%	13%	0%
Eritrea	68	9%	28%	19%	40%	1%	3%

Country	Hemophilia A	0–4	5–13	14–18	19–44	45+	Age not known
Estonia	108	10%	8%	1%	60%	19%	1%
Ethiopia	185	4%	38%	16%	41%	2%	0%
France	7,623	5%	14%	9%	39%	33%	0%
Georgia	289	4%	19%	8%	45%	23%	0%
Ghana	364	21%	49%	16%	5%	2%	7%
Guyana	23		39%	4%	43%	13%	0%
Honduras	324	10%	23%	14%	44%	3%	6%
Hong Kong	126	2%	15%	13%	57%	11%	1%
Hungary	892	3%	8%	5%	35%	50%	0%
India	21,350	2%	14%	11%	44%	11%	18%
Indonesia	2,425	6%	30%	18%	40%	4%	1%
Iran	5,498	4%	12%	8%	54%	22%	0%
Iraq	2,024	21%	40%	22%	14%	3%	0%
Ireland	685	6%	17%	9%	37%	31%	0%
Israel	638	13%	17%	9%	39%	22%	0%
Jamaica	79	13%	20%	11%	37%	19%	0%
Kenya	623	18%	30%	26%	13%	11%	3%
Korea, Republic of	1,778	3%	11%	7%	52%	27%	0%
Kyrgyzstan	146				91%	9%	0%
Latvia	99	3%			47%	21%	28%
Lebanon	191	9%	18%	8%	43%	20%	1%
Lithuania	165	0%	0%	0%	0%	0%	100%
Luxembourg	16	13%	13%	13%	38%	19%	6%
Madagascar	81	10%	33%	16%	35%	6%	0%
Malawi	27	0%	33%	22%	44%	0%	0%
Malaysia	974	9%	23%	12%	42%	13%	1%
Maldives	15	7%	20%	20%	33%	20%	0%
Mali	148	9%	51%	20%	16%	1%	3%
Mauritius	84	4%	4%	10%	48%	32%	4%
Mexico	4,867	1%	10%	11%	50%	18%	9%
Mongolia	88	13%	39%	16%	30%	3%	0%
Montenegro	42	2%	14%	7%	36%	40%	0%
Morocco	749	13%	25%	15%	42%	5%	0%
Nepal	608	8%	21%	14%	43%	9%	5%
Netherlands	1,376	3%	12%	7%	35%	43%	0%
New Zealand	604	2%	7%	7%	22%	30%	32%
Nigeria	645	4%	36%	16%	26%	2%	16%
Norway	349	2%	12%	9%	40%	35%	3%

Country	Hemophilia A	0–4	5–13	14–18	19–44	45+	Age not known
Pakistan	2,385	5%	29%	15%	43%	5%	4%
Palestine	292	4%	16%	8%	36%	13%	23%
Panama	284	5%	15%	8%	51%	20%	0%
Paraguay	397	10%	18%	15%	43%	14%	0%
Philippines	1,208	5%	13%	12%	50%	8%	12%
Portugal	794	3%	10%	6%	36%	29%	15%
Qatar	53	13%	25%	28%	32%	2%	0%
Saudi Arabia	920	23%	38%	17%	21%	1%	0%
Senegal	282	12%	37%	15%	31%	5%	0%
Serbia	476	4%	13%	4%	49%	30%	0%
Singapore	223	4%	11%	5%	40%	39%	0%
Slovakia	613	3%	9%	6%	42%	41%	0%
Slovenia	235	4%	10%	6%	32%	47%	0%
South Africa	2,021	1%	14%	10%	42%	29%	4%
Spain	1,822	2%	9%	8%	62%	20%	0%
Sri Lanka	956	20%	7%	6%	22%	5%	40%
Sudan	1,120	22%	35%	13%	26%	4%	0%
Suriname	14	14%	21%	0%	50%	14%	0%
Sweden	815	6%	14%	8%	42%	30%	0%
Syria	876	6%	31%	19%	37%	5%	2%
Tanzania	135	9%	24%	13%	12%	1%	41%
Thailand	1,710	8%	28%	14%	37%	13%	0%
Togo	35	9%	29%	20%	34%	9%	0%
Trinidad and Tobago	55	2%	24%	7%	33%	16%	18%
Tunisia	223	9%	22%	13%	48%	9%	0%
Uganda	272	34%	38%	9%	15%	3%	0%
United Kingdom	7,064	6%	13%	7%	39%	36%	0%
United States of America	14,098	8%	23%	12%	38%	19%	0%
Uruguay	235	3%	20%	11%	36%	23%	7%
Uzbekistan	1,580	9%	23%	9%	49%	10%	0%
Venezuela	2,289	1%	10%	8%	43%	21%	16%
Vietnam	3,379	6%	18%	11%	53%	12%	0%
Zambia	162	15%	30%	23%	15%	2%	14%
Zimbabwe	171	0%	10%	6%	25%	4%	56%

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

(106 countries reported age data for hemophilia B)

Country	Hemophilia B	0–4	5–13	14–18	19–44	45+	Age not known
Afghanistan	68	3%	31%	47%	16%	3%	0%
Albania	37	0%	11%	3%	68%	19%	0%
Algeria	555	4%	21%	30%	40%	5%	0%
Angola	12	8%	67%	8%	17%		0%
Argentina	392	2%	13%	13%	49%	21%	3%
Armenia	27	30%	15%	4%	26%	26%	0%
Australia	549	4%	10%	10%	37%	40%	0%
Austria	148	5%	16%	11%	38%	30%	0%
Bahamas	1	0%	0%	0%	100%	0%	0%
Bahrain	10	10%	20%	20%	10%	40%	0%
Bangladesh	413	21%	34%	17%	25%	2%	0%
Barbados	11	9%	9%	9%	45%	27%	0%
Belgium	250	1%	8%	7%	34%	50%	0%
Belize	5				100%		0%
Benin	4	0%	50%	25%	0%	25%	0%
Bolivia	28	25%	25%	14%	29%	7%	0%
Botswana	8	13%	25%	25%	38%	0%	0%
Brazil	2,196	5%	14%	9%	50%	23%	0%
Burkina Faso	29	28%	34%	17%	21%	0%	0%
Cambodia	42	17%	36%	19%	21%	7%	0%
Cameroon	35	23%	37%	14%	23%	3%	0%
Canada	727	3%	10%	7%	40%	40%	0%
Chile	186	7%	14%	10%	48%	21%	0%
Colombia	711	4%	13%	8%	61%	14%	0%
Congo, Republic of the	11	0%	27%	18%	55%	0%	0%
Costa Rica	43	5%	19%	2%	60%	14%	0%
Côte d'Ivoire	18	11%	44%	28%	11%	6%	0%
Croatia	68	0%	18%	6%	60%	16%	0%
Cuba	84	6%	13%	7%	46%	27%	0%
Czech Republic	143	5%	13%	8%	31%	43%	0%
Dominican Republic	42	0%	29%	5%	57%	10%	0%
Egypt	1,210	6%	21%	13%	46%	14%	0%
El Salvador	24	25%	38%	17%	13%	8%	0%

Country	Hemophilia B	0–4	5–13	14–18	19–44	45+	Age not known
Eritrea	7	14%	43%	0%	43%	0%	0%
Estonia	11	9%	27%	9%	27%	27%	0%
Ethiopia	33	3%	30%	15%	48%	3%	0%
France	1,841	5%	15%	10%	35%	34%	0%
Georgia	57	11%	19%	5%	37%	28%	0%
Ghana	28	32%	46%	18%	4%		0%
Guyana	1					100%	0%
Honduras	36	3%	31%	22%	42%	3%	0%
Hong Kong	23	4%	13%	13%	35%	35%	0%
Hungary	243	3%	5%	3%	39%	49%	0%
India	3,475	3%	14%	11%	48%	12%	13%
Indonesia	378	7%	34%	21%	31%	2%	5%
Iran	1,162	3%	11%	8%	57%	21%	0%
Iraq	543	21%	40%	21%	14%	5%	0%
Ireland	223	4%	11%	12%	39%	35%	0%
Israel	110	16%	16%	15%	35%	17%	0%
Jamaica	12	25%	17%	17%	25%	17%	0%
Kenya	151	26%	26%	28%	16%	3%	1%
Korea, Republic of	446	1%	13%	9%	50%	27%	0%
Kyrgyzstan	37				81%	19%	0%
Latvia	23	0%			57%	22%	22%
Lebanon	54	4%	19%	13%	50%	15%	0%
Lithuania	27	0%	0%	0%	0%	0%	100%
Luxembourg	4	0%	50%	0%	25%	0%	25%
Madagascar	64	8%	45%	19%	27%	2%	0%
Malawi	5	0%	60%	20%	20%	0%	0%
Malaysia	166	10%	19%	11%	43%	16%	1%
Maldives	4	0%	0%	75%	0%	25%	0%
Mali	17	24%	41%	24%	12%	0%	0%
Mauritius	9	11%	22%	0%	56%	11%	0%
Mexico	728	2%	11%	12%	51%	18%	7%
Mongolia	32	13%	38%	6%	38%	6%	0%
Montenegro	4	0%	0%	0%	75%	25%	0%
Morocco	139	10%	22%	10%	54%	4%	0%
Nepal	110	3%	20%	23%	36%	14%	5%
Netherlands	198	4%	12%	9%	37%	39%	0%
New Zealand	141	4%	6%	6%	19%	31%	35%

Country	Hemophilia B	0–4	5–13	14–18	19–44	45+	Age not known
Nigeria	27	15%	56%	15%	7%	0%	7%
Norway	104	3%	13%	7%	42%	35%	0%
Pakistan	416	6%	27%	13%	46%	6%	3%
Palestine	60	5%	20%	3%	38%	15%	18%
Panama	35	6%	14%	9%	57%	14%	0%
Paraguay	39	5%	26%	21%	26%	23%	0%
Philippines	214	6%	16%	9%	54%	6%	9%
Portugal	212	2%	8%	7%	32%	26%	25%
Qatar	10	30%	10%	30%	30%	0%	0%
Saudi Arabia	208	24%	37%	12%	27%	0%	0%
Senegal	41	17%	41%	24%	15%	2%	0%
Serbia	89	3%	15%	7%	52%	24%	0%
Singapore	46	0%	17%	9%	52%	22%	0%
Slovakia	93	5%	15%	9%	48%	23%	0%
Slovenia	33	3%	3%	12%	39%	42%	0%
South Africa	398	4%	17%	9%	43%	26%	2%
Spain	282	1%	6%	6%	34%	45%	7%
Sri Lanka	231	20%	18%	7%	7%	8%	39%
Sudan	273	21%	39%	16%	22%	2%	0%
Suriname	2	0%	0%	0%	0%	0%	100%
Sweden	216	3%	13%	7%	39%	37%	0%
Syria	103	14%	28%	19%	35%	2%	2%
Tanzania	22	9%	36%	9%	14%		32%
Thailand	226	10%	27%	16%	29%	19%	0%
Togo	2		0%		100%		0%
Trinidad and Tobago	13	0%	23%	15%	38%	23%	0%
Tunisia	60	15%	25%	18%	23%	18%	0%
Uganda	44	27%	45%	11%	16%		0%
United Kingdom	1,607	5%	15%	6%	37%	37%	0%
United States of America	4,300	10%	21%	12%	33%	24%	0%
Uruguay	38	3%	24%	8%	53%	11%	3%
Uzbekistan	189	20%	21%	9%	44%	5%	0%
Venezuela	616	1%	9%	9%	40%	25%	15%
Vietnam	699	5%	19%	11%	52%	14%	0%
Zambia	34	26%	18%	32%	15%	0%	9%
Zimbabwe	13	0%	8%	0%	23%	15%	54%

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

(30 countries reported age data)

Country	Hemophilia type unknown	0–4	5–13	14–18	19–44	45+	Age not known
Afghanistan	7	29%	57%	14%			
Argentina	3	0%	0%	0%	67%	33%	0%
Bahamas	1	100%	0%	0%	0%	0%	0%
Bangladesh	6			100%			
Belgium	8	0%	0%	0%	13%	88%	0%
Benin	18	6%	44%	0%	33%	0%	17%
Cameroon	3	100%	0%	0%	0%	0%	0%
Chile	51	0%	0%	4%	57%	39%	
Dominican Republic	14	0%	14%	7%	64%	7%	7%
Egypt	1,477	8%	21%	14%	48%	9%	
Ethiopia	169	3%	41%	20%	36%	0%	0%
Ghana	57	42%	23%	19%	16%		
Honduras	25	0%	28%	8%	20%	4%	40%
Hong Kong	2				100%		
India	559	0%	3%	4%	30%	6%	57%
Indonesia	136	2%	29%	3%	27%	1%	37%
Iran	3,945	4%	18%	10%	52%	16%	0%
Korea, Republic of	40	3%	5%	8%	35%	50%	0%
Malawi	63	22%	40%	10%	22%	0%	6%
Mexico	297	0%	3%	5%	26%	17%	49%
Morocco	1	0%	0%	0%	100%	0%	0%
Nigeria	23	9%	30%	9%	0%	9%	43%
Philippines	211	2%	9%	12%	46%	6%	26%
Sweden	2	0%	0%	0%	0%	50%	50%
Tanzania	26	15%	38%	15%	19%		12%
Togo	10		40%		30%		30%
Uganda	3	33%	67%				
Uruguay	8	0%	0%	25%	75%	0%	0%
Uzbekistan	10			100%			
Zambia	80	0%	3%	91%	0%	0%	6%

TABLE 13. **Age distribution: VWD**

(88 countries reported age data)

Country	Total number of patients	0–4	5–13	14–18	19–44	45+	Age not known
Afghanistan	7			100%			
Albania	8	0%	0%	13%	63%	25%	0%
Argentina	399	0%	0%	2%	41%	43%	15%
Armenia	16	13%	19%	19%	44%	6%	0%
Australia	2,460	1%	8%	7%	43%	41%	0%
Bahamas	2	0%	0%	0%	100%	0%	0%
Bahrain	300	5%	10%	20%	31%	34%	0%
Bangladesh	5	20%	40%	0%	40%	0%	
Barbados	3			33%	33%	33%	
Belgium	2,274	1%	8%	11%	42%	39%	0%
Benin	7	14%	29%	0%	57%	0%	0%
Bolivia	3		67%		33%		
Botswana	7	0%	43%	57%	0%	0%	0%
Brazil	10,231	1%	8%	8%	54%	29%	0%
Cambodia	7	0%	57%	43%	0%	0%	0%
Cameroon	5	0%	0%	0%	60%	40%	0%
Canada	4,901	1%	7%	7%	48%	37%	0%
Colombia	3,654	4%	12%	17%	54%	13%	0%
Costa Rica	94	0%	0%	5%	46%	47%	2%
Côte d'Ivoire	3	33%	0%	0%	33%	33%	0%
Croatia	188	2%	4%	11%	46%	38%	
Cuba	485	3%	11%	30%	40%	17%	
Czech Republic	803	1%	7%	7%	42%	42%	0%
Dominican Republic	52	0%	6%	6%	71%	0%	17%
Egypt	649	6%	20%	10%	48%	16%	
El Salvador	2		50%		50%		
Estonia	128	3%	21%	9%	45%	15%	7%
France	3,306	3%	13%	11%	37%	36%	0%
Georgia	64	5%	16%	16%	44%	20%	
Ghana	11	27%	36%	0%	36%		
Honduras	21	0%	29%	5%	52%	10%	5%
Hong Kong	4		25%		50%	25%	

Country	Total number of patients	0–4	5–13	14–18	19–44	45+	Age not known
Hungary	1,452	1%	7%	6%	34%	51%	0%
India	927	1%	18%	11%	49%	10%	10%
Indonesia	20	5%	25%	5%	30%	5%	30%
Iran	1,832	2%	15%	12%	53%	17%	0%
Iraq	704	16%	31%	32%	17%	3%	
Ireland	1,859	4%	19%	9%	41%	27%	0%
Jamaica	3					100%	
Kenya	39	13%	44%	28%	13%	3%	0%
Korea, Republic of	165	4%	8%	9%	56%	23%	0%
Kyrgyzstan	20			50%	50%		
Latvia	90	1%			47%	11%	41%
Lebanon	183	3%	21%	8%	51%	14%	4%
Lithuania	310	0%	0%	0%	0%	0%	100%
Luxembourg	1	0%	0%	0%	0%	0%	100%
Madagascar	2	0%	0%	50%	0%	50%	0%
Mali	17	24%	24%	24%	18%	12%	0%
Mauritius	1	0%	100%	0%	0%	0%	0%
Mexico	367	1%	8%	12%	41%	17%	20%
Mongolia	20	15%	25%	15%	30%	15%	
Montenegro	3	0%	0%	0%	100%	0%	0%
Morocco	196	3%	17%	5%	58%	17%	0%
Nepal	10	10%	40%	10%	20%	10%	10%
Netherlands	583	3%	14%	11%	30%	42%	0%
New Zealand	625	0%	0%	1%	6%	8%	84%
Nigeria	13	0%	23%	8%	46%	0%	23%
Norway	467	0%	2%	4%	39%	55%	0%
Pakistan	491	6%	32%	15%	44%	3%	0%
Palestine	60	2%	22%	12%	47%	2%	17%
Panama	537	0%	12%	16%	57%	15%	0%
Paraguay	4	0%	25%	0%	75%	0%	0%
Philippines	50	2%	10%	10%	28%	6%	44%
Portugal	984	1%	10%	6%	35%	35%	13%
Saudi Arabia	432	21%	37%	22%	19%	2%	
Senegal	14	0%	21%	36%	36%	7%	0%
Serbia	322	1%	10%	3%	49%	36%	0%

Country	Total number of patients	0–4	5–13	14–18	19–44	45+	Age not known
Singapore	94	0%	11%	7%	32%	50%	
Slovakia	776	1%	5%	5%	51%	37%	
Slovenia	207	1%	8%	6%	52%	33%	0%
South Africa	671	0%	3%	6%	42%	45%	4%
Spain	720	0%	2%	1%	25%	55%	17%
Sri Lanka	72	13%	26%	7%	11%	11%	32%
Sudan	410	23%	34%	16%	24%	3%	
Suriname	3	0%	0%	0%	67%	33%	0%
Sweden	962	3%	8%	6%	40%	43%	0%
Syria	151	13%	28%	15%	36%	7%	0%
Tanzania, United Republic of	5	0%		20%	20%		60%
Trinidad and Tobago	10				10%	10%	80%
Tunisia	128	3%	19%	11%	48%	20%	0%
Uganda	2			50%		50%	
United Kingdom	11,341	2%	10%	7%	40%	40%	0%
United States of America	13,535	6%	28%	23%	29%	15%	0%
Uruguay	263	0%	0%	2%	2%	2%	95%
Uzbekistan	271	10%	41%	20%	18%	10%	
Venezuela	1,199	1%	7%	11%	49%	30%	3%
Vietnam	192	4%	27%	12%	43%	14%	0%
Zambia	5	0%	0%	80%	0%	20%	0%

TABLE 14. **HIV and HCV infection**

(75 countries reported HIV and/or HCV data)

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

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

	Total number of people living with HIV			Total number of people infected with hepatitis C*			Total number of people with currently active hepatitis C**		
	Hemophilia	VWD	Other bleeding disorders	Hemophilia	VWD*	Other bleeding disorders	Hemophilia	VWD	Other bleeding disorders
Albania	1	0	0	36	0	0	12	0	0
Algeria	0	0	0						
Argentina	54	0	0	588	20	0			
Armenia	0	1	0	62	0	0	2	0	0
Austria	44	0	0	191	0	0			
Bahamas	0	0	0	0	0	0	0	0	0
Bahrain	0	0	0	0	0	0	0	0	0
Barbados	0	0		0	0		0	0	
Botswana	3	0	0	0	0	0	0	0	0
Burkina Faso	0								
Chile	3	0	0						
Colombia	12	2	0	192	50	0	25	7	0
Congo, Republic of the	0	0	0	0	0	0			
Costa Rica	11	0	0	15	0	0	0	0	0
Côte d'Ivoire	1	0	0	0	0	0	0	0	0
Croatia	3	0	0						
Cuba	3	0	0	133	3	2	115	3	2
Czech Republic	2	0	0	181	5	1	46	1	0
Dominican Republic				28	0	8	20	0	8
El Salvador	0	0	0	0	0	0	0	0	0
Estonia	1			28	1				
France	545	20	5	2147	194	53	42	6	0
Ghana	0	0	0	0	0	0	0	0	0
Guyana	0	0	0	1	0	0	0	0	0
Honduras	0	1	0						
Hong Kong	1			6					

	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
Hungary	10	0	0	374	115	0			
India	29	2	0	84	3	0			
Iran	24	1	1	1069	152	155			
Iraq	0	0	0	306	70				
Ireland	29	0	0	140	8	2	3	0	0
Israel	20	0					8	0	0
Jamaica	1	0	0	2	0	0	1	0	0
Japan	694	7	3	1640	110	66	888	59	40
Korea, Republic of	1	0	0	544	2	5	62	0	1
Kyrgyzstan	0	0		50			20		
Lebanon	0	0	0	10	0	0	2	0	0
Luxembourg	1	0	0				0	0	0
Madagascar	0	0	0	0	0	0	0	0	0
Malaysia	10	0	0	25	1	0	25	1	0
Mali	0	0	0	0	0	0	0	0	0
Mauritius	0	0	0	7	0	0	7	0	0
Mexico	42	3	0	264	6	0			
Montenegro	0	0	0	3	0	0	0	0	0
Morocco	0	0	0	84	1	0	3	0	0
Netherlands	8	0	0	184	5	9	12	0	0
New Zealand	4	0	0	1	0	0	1	0	0
Norway									
Pakistan	15	0	4	269	66	10	269	66	10
Panama	0	0	0	0	0	0	0	0	0
Portugal	31	1	0	135	15	4	1	0	0
Qatar	0	0	0	0	0	0	0	0	0
Saudi Arabia	0			1			1		
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	
Slovakia	0	0	0	120	12	12	14	1	0
Slovenia	7	0	0	96	6	0	0	0	0
South Africa	80	3	1	213	3	2			
Spain	432	27	11						

	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
Sri Lanka				2			2		
Sudan	2	1	1	42					
Suriname	0	0	0	0	0	0	0	0	0
Sweden	29	0	0						
Syria				71	6				
Thailand	15	0	0	44	0	0	0	0	0
Trinidad and Tobago	0	0	0	3	0	0	3	0	0
Tunisia	10	0		72	0		0	0	
Uganda	0	1	0	0	0	0	0	0	0
United Kingdom	258	4	1	1526	168	29	64	10	2
United States of America	810	13	6	1348	63	27			
Uzbekistan	8	0	0	2	10	0	0	0	0
Venezuela	18	4	0	351	23	9	150	15	5
Vietnam	5	0	0	353	13	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**

(100 countries reported prophylaxis data)

Country	Percent under 18 on prophylaxis	Precise or estimate	Percent over 18 on prophylaxis	Precise or estimate
Albania	50	Estimate	0	Estimate
Algeria	95	Estimate	50	Estimate
Argentina	85	Estimate	15	Estimate
Armenia	99	Precise	50	Precise
Australia	97	Estimate	87	Estimate
Austria	87	Precise	80	Precise
Bahamas	0	Precise	2	Precise
Bahrain	100	Precise	50	Precise
Barbados	4	Precise	1	Precise
Belgium	100	Estimate	90	Estimate
Belize			2	Estimate
Benin	9	Precise	10	Precise
Botswana	100	Precise	50	Estimate
Brazil	65	Precise	74	Precise
Burkina Faso	25	Precise	23	Precise
Cambodia	70	Estimate	20	Estimate
Cameroon	4	Precise	2	Precise
Canada	94	Estimate	86	Estimate
Chile	100	Precise	50	Estimate
Colombia	99	Precise	88	Precise
Congo, Republic of the	38	Estimate	0	Precise
Costa Rica	75	Precise	60	Precise
Côte d'Ivoire	27	Precise	2	Precise
Croatia	100	Precise	93	Precise
Cuba	15	Precise	8	Precise
Czech Republic	90	Precise	78	Precise
Dominican Republic	42	Estimate	0	Estimate
Egypt	20	Estimate		
El Salvador	80	Estimate	40	Estimate
Eritrea	90	Estimate	0	Precise
Estonia	88	Precise	40	Precise
Ethiopia	0	Precise	0	Precise
Finland	95	Estimate		
France	83	Precise	68	Precise

Country	Percent under 18 on prophylaxis	Precise or estimate	Percent over 18 on prophylaxis	Precise or estimate
Georgia	58	Estimate	20	Estimate
Ghana	80	Estimate	50	Estimate
Guyana	90	Estimate	100	Precise
Hong Kong	82	Estimate	68	Estimate
Hungary	100	Precise	70	Estimate
Indonesia	0	Precise	0	Precise
Iran	51	Estimate	21	Estimate
Iraq	60	Estimate	50	Estimate
Ireland	96	Estimate	95	Estimate
Israel	95	Precise	85	Precise
Jamaica	12	Precise	10	Precise
Japan	90	Estimate	80	Estimate
Kenya	11	Precise	10	Precise
Korea, Republic of	61	Precise	51	Precise
Kuwait	90	Estimate		
Kyrgyzstan	0	Precise	0	Precise
Latvia	100	Estimate	100	Estimate
Lebanon	53	Precise	28	Precise
Lesotho	0	Estimate	0	Estimate
Lithuania	100	Precise	80	Precise
Luxembourg	100	Precise	100	Precise
Madagascar	38	Estimate	20	Estimate
Malawi	30	Estimate	22	Estimate
Malaysia	50	Estimate	80	Estimate
Maldives	2	Estimate		
Mali	75	Estimate	10	Precise
Malta	100	Precise	94	Precise
Mauritius	0	Precise	100	Precise
Mexico	96	Precise	27	Precise
Montenegro	100	Precise	100	Precise
Netherlands	97	Estimate	92	Estimate
New Zealand	97	Estimate	90	Estimate
Nigeria	55	Estimate	1	Precise
Norway	98	Estimate	98	Estimate
Pakistan	3	Estimate	0	Precise
Palestine	65	Estimate	25	Estimate
Panama	100	Precise	80	Precise
Paraguay	80	Estimate	30	Estimate

Country	Percent under 18 on prophylaxis	Precise or estimate	Percent over 18 on prophylaxis	Precise or estimate
Philippines	0	Precise	0	Precise
Qatar	80	Precise	80	Precise
Romania	100	Precise	39	Precise
Russia	90	Estimate	65	Estimate
Saudi Arabia	30	Estimate	50	Estimate
Senegal	59	Precise	28	Precise
Serbia	95	Precise	90	Precise
Singapore	66	Precise	35	Precise
Slovakia	98	Precise	75	Precise
Slovenia	100	Estimate	95	Estimate
South Africa	50	Estimate	30	Estimate
Sri Lanka	45	Precise		
Suriname	20	Precise	33	Precise
Sweden	95	Estimate	90	Estimate
Syria	9	Precise	1	Precise
Tanzania	36	Estimate		
Thailand	28	Precise	11	Precise
Togo	58	Estimate	16	Estimate
Trinidad and Tobago	67	Precise	32	Precise
Tunisia	79	Precise	54	Precise
Uganda	6	Precise	1	Precise
Ukraine	40	Estimate		
United Kingdom	95	Precise	90	Estimate
Uruguay	88	Estimate	53	Estimate
Uzbekistan	95	Precise	90	Precise
Venezuela	25	Estimate	15	Estimate
Vietnam	14	Estimate	2	Estimate
Zambia	29	Precise	29	Precise

TABLE 16. **Use of Factor Concentrates in 2021: Factor VIII**

(102 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 2021 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.

Country	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	629,750	0	0	0	0	0	0	629,750	629,750		0.0158	0
Albania	7,400,000	3,000,000	100,000		41	1	0	4,300,000			2.6319	1.1025
Algeria	119,188,750	76,856,750	42,332,000		64	36	0	0			2.6714	2.6714
Angola	446,500							446,500	446,500		0.0132	
Argentina	239,555,000	134,500,000	101,000,000	4,000,000	56	42	2	55,000			5.2295	5.2283
Armenia	4,367,000	2,267,000	0	0	52	0	0	2,100,000	1,000,000	1,000,000	1.4713	0.7638
Australia	158,963,400	16,562,550	86,098,600	56,302,250	10	54	35				6.1759	6.1759
Bahamas	173,519	0	0	0	0	0	0	173,519	137,500		0.4372	0
Bahrain	7,000,000	0	7,000,000	0	0	100	0	0			4.0039	4.0039
Bangladesh	15,277,250	1,800,000			12	0	0	13,477,250	10,427,250	3,050,000	0.0919	0.0108
Barbados	338,500							338,500	338,500		1.1765	
Belize	200,000							200,000	100,000	100,000	0.4939	
Benin	315,000	0	0	0	0	0	0	315,000	315,000		0.0253	0
Bolivia	2,419,000							2,419,000	1,956,500	462,500	0.2044	
Brazil	944,294,250	203,268,000	741,026,250		22	78	0				4.4127	4.4127
Burkina Faso	200,000	0	0	0	0	0	0	200,000		200,000	0.0093	0
Cambodia	1,441,000							1,441,000	916,000	525,000	0.0850	
Cameroon	1,990,500	0	0	0	0	0	0	1,990,500	1,140,500	850,000	0.0731	0
Canada	297,118,368	34,138,141	168,526,048	94,454,179	11	57	32	0			7.7686	7.7686
Chile	66,538,750	66,538,750	0	0	100	0	0	0			3.4633	3.4633

Country	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
Colombia	256,423,000	60,525,000	181,448,000	14,430,000	24	71	6	20,000			5.0018	5.0014
Congo, Republic of the	1,433,000	0	0	0	0	0	0	1,433,000	1,433,000		0.0155	0
Costa Rica	19,449,750	19,449,750	0	0	100	0	0	0			3.7847	3.7847
Côte d'Ivoire	2,057,000	0	0	0	0	0	0	2,057,000	350,000	650,000	0.0760	0
Cuba	4,195,500	2,525,000			60	0	0	1,670,500	1,000,000		0.3707	0.2231
Czech Republic	61,219,295	4,514,671	20,442,152	36,262,473	7	33	59	0			5.7196	5.7196
Dominican Republic	3,429,250							3,429,250	2,260,000	1,169,250	0.3131	
Egypt	113,515,000	59,000,000	40,000,000	0	52	35	0	14,515,000	3,750,000	3,265,000	1.0888	0.9496
El Salvador	2,600,000							2,600,000	900,000	1,700,000	0.3989	
Eritrea	447,100	0	0	0	0	0	0	447,100	225,000		0.1226	0
Estonia	8,632,750	1,625,250	14,700	6,861,500	19	0	79				6.4944	6.4944
Ethiopia	4,102,250	0	0	0	0	0	0	4,102,250	2,857,250	1,245,000	0.0348	0
Finland	41,789,250	1,461,000	13,553,000	26,775,250	3	32	64				7.5409	7.5409
France	362,237,800	27,213,250	144,444,550	190,580,000	8	40	53	0			5.3665	5.3665
Georgia	17,716,500	17,716,500		545	100	0	0				4.7771	4.7771
Germany	641,274,934	171,620,294			27	0	0	0			7.7142	7.7142
Ghana	3,910,480	0	0	0	0	0	0	3,910,480	2,700,000	1,150,000	0.1232	0
Guyana	1,180,000							1,180,000	1,180,000		1.4930	
Honduras	1,100,000							1,100,000	800,000	300,000	0.1093	
Hungary	126,775,000	44,935,000	61,552,000	20,288,000	35	49	16				13.0563	13.0563
India	312,063,250	105,000,000	129,000,000		34	41	0	78,063,250	54,519,750	23,543,500	0.2240	0.1679
Indonesia	3,450,000							3,450,000	3,100,000	350,000	0.0125	
Iraq	50,000,000	0	50,000,000	0	0	100	0	0			1.2142	1.2142
Ireland	25,881,000	0	84,500	25,796,500	0	0	100	0			5.1471	5.1471
Jamaica	1,200,000	0	0	0	0	0	0	1,200,000	500,000	150,000	0.4036	0
Japan	649,901,000	48,495,000	198,855,000	402,551,000	7	31	62	0			5.1710	5.171
Jordan	6,032,000							32,000	32,000		0.5874	0.5843
Kenya	9,500,000	0	0	0	0	0	0	9,500,000	6,550,000	2,950,000	0.1728	0
Korea, Republic of	285,000,000	50,000,000	235,000,000		18	82	0				5.5078	5.5078
Kyrgyzstan	8,075,000	2,400,000	0	0	30	0	0	5,675,000	3,238,000	2,437,500	1.2063	0.3585
Latvia	9,615,500	634,000	7,755,500	1,226,000	7	81	13	0			5.1060	5.106

Country	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	14,121,000			0	0	0	0	2,891,000	2,867,000	24,000	2.0861	1.659
Lithuania	29,433,500	6,128,500	17,271,000	6,034,000	21	59	21	0			10.5296	10.5296
Madagascar	2,281,000	0	0	0	0	0	0	2,281,000	1,352,500	150,000	0.0802	0
Malawi	1,056,750	0	0	0	0	0	0	1,056,750	806,750	250,000	0.0538	0
Malaysia	34,754,300	34,754,300			100	0	0	0			1.0604	1.0604
Maldives	400,000							400,000	300,000		0.7358	
Mali	1,672,000	0	0	0	0	0	0	1,672,000	742,000	375,000	0.0802	0
Mauritius	5,026,500	5,026,500			100	0	0	0			3.9702	3.9702
Mexico	389,703,000	27,200,500	360,196,000		7	92	0	2,306,500			2.9917	2.974
Mongolia	2,332,500	0			0	0	0	2,235,500	1,723,000	512,500	0.7006	0.0291
Montenegro	1,650,000	1,650,000			100	0	0	0			2.6605	2.6605
Morocco	33,826,000	21,039,500	10,786,500		62	32	0	2,000,000	2,000,000		0.9058	0.8522
Nepal	5,146,250							5,146,250	4,170,250	976,000	0.1734	
Netherlands	88,967,000	170,000	57,928,500	30,868,500	0	65	35				5.0741	5.0741
Nigeria	7,861,250	0	0	0	0	0	0	7,861,250	4,791,000	3,070,250	0.0372	0
Pakistan	9,773,750	760,000	0	0	8	0	0	9,013,750	4,900,000	4,100,000	0.0434	0.0034
Palestine	5,264,500							700,000			1.0694	0.9272
Panama	10,249,500	9,620,750	522,750	106,000	94	5	1	0			2.3392	2.3392
Paraguay	2,693,250	102,000			4	0	0	2,591,250	1,141,250	1,450,000	0.3730	0.0141
Philippines	4,420,000	1,570,000	0	0	36	0	0	2,850,000			0.0398	0.0141
Poland*	351,190,237	316,345,400	34,844,837	0	90	10	0				9.2954	9.2954
Portugal	117,442,000		16,147,250	101,294,750	0	14	86				11.4028	11.4028
Qatar	18,800,000	0	18,800,000	4,500,000	0	100	24				6.4152	6.4152
Romania	79,897,295	44,939,700	32,021,060	1,412,250	56	40	2	0			4.1798	4.1798
Russia	1,125,117,048	508,305,180	590,156,918	26,654,950	45	52	2				7.8435	7.8435
Saudi Arabia	148,120,000	57,960,000	24,000,000	66,160,000	39	16	45				4.1912	4.1912
Senegal	980,000	0	0	0	0	0	0	980,000	680,000	300,000	0.0570	0
Serbia	32,517,250	4,633,250	26,593,000	0	14	82	0	1,291,000			4.7512	4.5625
Singapore	14,406,200	2,185,500	12,220,700	0	15	85	0	0			2.6416	2.6416
Slovakia	48,500,000	21,150,000	18,850,000	8,500,000	44	39	18	0			8.9036	8.9036
Slovenia	13,117,000	743,500	2,352,500	10,021,000	6	18	76				6.2254	6.2254
South Africa	62,274,314	61,239,400	1,034,914	0	98	2	0	0			1.0372	1.0372

Country	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	27,290,500	8,391,000			31	0	0	18,899,500	15,163,500	3,736,000	1.2317	0.3787
Sudan	10,255,000	10,255,000			100	0	0				0.2283	0.2283
Suriname	50,000							50,000	50,000		0.0845	
Sweden	102,310,500	0	53,022,000	49,288,500	0	52	48	0			9.8226	9.8226
Syria	9,859,500							9,859,500	9,859,500		0.5395	
Tanzania	1,426,000	0	0	0	0	0	0	1,426,000			0.0232	0
Thailand	49,383,500	31,200,500	11,926,000		63	24	0	6,257,000	6,527,000		0.7060	0.6165
Togo	315,750							315,750	315,750		0.0372	
Trinidad and Tobago	1,020,000							1,020,000	1,020,000		0.7268	
Tunisia	10,826,750	4,036,750	0	0	37	0	0	0			0.9071	0.9071
Uganda	1,222,000							1,222,000	922,000	300,000	0.0259	
Ukraine	74,459,500	51,666,500	22,393,000	0	69	30	0	400,000	400,000		1.6994	1.6903
United Kingdom	426,482,451	3,744,000	284,876,261	137,862,190	1	67	32	0			6.3345	6.3345
United States of America	1,787,000,000	109,000,000	1,159,000,000	519,000,000	6	65	29				5.3843	5.3843
Uruguay	9,031,700	9,031,700	0	0	100	0	0	0			2.5915	2.5915
Uzbekistan	23,828,250	12,790,500	0	0	54	0	0	11,037,750	7,487,750	3,550,000	0.6825	0.3663
Venezuela	23,913,250	8,000,000			33	0	0	15,913,250	13,996,250	1,917,000	0.8331	0.2787
Vietnam	22,531,650	12,056,400	10,475,250	0	54	46	0	0			0.2295	0.2295
Zambia	2,313,750							2,313,750	1,610,000	703,750	0.1223	
Zimbabwe	2,716,500							2,716,500	1,780,250	936,250	0.1800	
TOTAL	**9,800,101,854**	**2,225,396,836**	**4,958,805,903**	**1,841,229,837**				**279,178,099**	**187,408,250**	**67,448,500**		

** 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 2021: Factor IX**

(95 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 2021 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.

Country	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	200,000							200,000	200,000	0	0.005	
Algeria	18,230,400	18,230,400			100	0	0				0.4086	0.4086
Argentina	21,300,000	12,000,000	7,700,000	1,600,000	56	36	8	0			0.465	0.465
Armenia	680,000	175,000	0	0	26	0	0	505,000	200,000	200,000	0.2291	0.059
Australia	26,706,500	392,000	10,348,250	15,966,250	1	39	60				1.0376	1.0376
Bahrain	2,500,000	0	0	2,500,000	0	0	100	0			1.43	1.43
Bangladesh	600,000							600,000	250,000	350,000	0.0036	
Belize	100,000							100,000	0	100,000	0.247	
Benin	50,000	0	0	0	0	0	0	50,000	50,000	0	0.004	0
Bolivia	150,000							150,000	0	150,000	0.0127	
Brazil	153,080,550	153,080,550	0	0	100	0	0				0.7154	0.7154
Burkina Faso	169,000	0	0	0	0	0	0	169,000	0	50,000	0.0079	0
Cambodia	763,250							763,250	650,000	113,250	0.045	
Cameroon	332,000	0	0	0	0	0	0	332,000	182,000	150,000	0.0122	0
Canada	51,693,520	3,581,209	30,812,801	17,299,510	7	60	33	0			1.3516	1.3516
Chile	16,515,600		0	0	0	0	0	0			0.8596	0.8596
Colombia	37,595,000	17,309,000	16,447,000	3,839,000	46	44	10	0			0.7333	0.7333
Congo, Republic of the	229,000	0	0	0	0	0	0	229,000			0.0025	0
Costa Rica	4,341,600	4,341,600	0	0	100	0	0	0			0.8448	0.8448
Côte d'Ivoire	402,000	0	0	0	0	0	0	402,000			0.0149	0
Cuba	240,000	0			0	0	0	240,000	240,000	0	0.0212	0

Country	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
Czech Republic	7,493,590	1,068,080	2,556,125	3,869,385	14	34	52	0			0.7001	0.7001
Dominican Republic	300,000							300,000	0	300,000	0.0274	
Egypt	1,000,000							1,000,000	0	1,000,000	0.0096	
El Salvador	500,000							500,000	0	500,000	0.0767	
Eritrea	4,200	0	0	0	0	0	0	4,200			0.0012	0
Estonia	685,600	685,600			100	0	0				0.5158	0.5158
Ethiopia	550,000	0	0	0	0	0	0	550,000	300,000	250,000	0.0047	0
Finland	7,150,750	817,000	3,289,500	3,044,250	11	46	43				1.2904	1.2904
France	64,991,750	2,035,500	6,624,500	56,331,750	3	10	87	0			0.9629	0.9629
Georgia	1,450,000	1,450,000			100	0	0				0.391	0.391
Germany	66,682,500	13,910,800	19,295,000	33,476,700	21	29	50	0			0.8022	0.8022
Ghana	425,000	0	0	0	0	0	0	425,000	300,000	125,000	0.0134	0
Honduras	250,000							250,000	0	250,000	0.0248	
Hungary	8,565,000	8,565,000	0	0	100	0	0				0.8821	0.8821
India	36,200,000	22,000,000	1,200,000	9,000,000	61	3	25	4,000,000	0	4,000,000	0.026	0.0231
Indonesia	500,000							500,000	250,000	250,000	0.0018	
Iraq	15,000,000	0	15,000,000	0	0	100	0	0			0.3643	0.3643
Ireland	10,031,500	0	0	10,031,500	0	0	100	0			1.995	1.995
Jamaica	100,000							100,000	0	25,000	0.0336	
Japan	111,806,000	15,448,000	21,926,000	74,432,000	14	20	67	0			0.8896	0.8896
Jordan	1,511,000							11,000	11,000	0	0.1471	0.1461
Kenya	1,754,000	0	0	0	0	0	0	1,754,000	1,054,000	700,000	0.0319	0
Korea, Republic of	74,000,000	3,000,000	71,000,000		4	96	0				1.4301	1.4301
Kyrgyzstan	1,535,500	1,000,000	0	0	65	0	0	535,500	323,000	212,500	0.2294	0.1494
Latvia	808,000	808,000	0	0	100	0	0	0			0.4291	0.4291
Lebanon	3,138,400			0	0	0	0	638,400	410,000	21,000	0.4636	0.3693
Lithuania	10,128,500	10,128,500	0	0	100	0	0	0			3.6234	3.6234
Madagascar	1,187,000	0	0	0	0	0	0	1,187,000	375,000	132,000	0.0418	0
Malawi	125,000	0	0	0	0	0	0	125,000	50,000	75,000	0.0064	0
Malaysia	8,261,000	8,261,000			100	0	0	0			0.252	0.252
Maldives	100,000							100,000	0	100,000	0.184	
Mali	260,000	0	0	0	0	0	0	260,000	190,000	0	0.0125	0

Country	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	235,000	235,000			100	0	0	0			0.1856	0.1856
Mexico	6,853,900	6,853,900			100	0	0	0			0.0526	0.0526
Mongolia	364,000	0			0	0	0	350,000	300,000	50,000	0.1093	0.0042
Montenegro	275,000	275,000			100	0	0	0			0.4434	0.4434
Morocco	3,071,250	1,738,500	1,332,752		57	43	0	0			0.0822	0.0822
Nepal	1,352,500							1,352,500	1,202,500	150,000	0.0456	
Netherlands	17,704,750	0	5,738,250	11,966,500	0	32	68				1.0098	1.0098
Nigeria	962,000	0	0	0	0	0	0	962,000	462,000	500,000	0.0046	0
Pakistan	960,000	510,000	0	0	53	0	0	450,000	0	450,000	0.0043	0.0023
Palestine	809,500							300,000	300,000	0	0.1644	0.1035
Panama	1,555,750	1,391,000	164,750	0	89	11	0	0			0.3551	0.3551
Paraguay	550,000							550,000	0	550,000	0.0762	
Philippines	696,000	0	0	0	0	0	0	696,000	48,000	648,000	0.0063	0
Poland*	45,641,800	40,501,800	5,140,000	0	89	11	0				1.2081	1.2081
Portugal	10,661,500		1,957,500	8,704,000	0	18	82				1.0352	1.0352
Qatar	5,700,000	3,800,000			67	0	0				1.945	1.945
Romania	7,475,050			1,524,000	0	0	20	0			0.3911	0.3911
Russia	146,231,550	104,554,050	41,677,500		71	29	0				1.0194	1.0194
Saudi Arabia	19,805,000	11,555,000	6,600,000	1,650,000	58	33	8	0			0.5604	0.5604
Senegal	375,000	0	0	0	0	0	0	375,000	150,000	150,000	0.0218	0
Serbia	4,085,800	551,800	3,534,000	0	14	86	0	0			0.597	0.597
Singapore	3,146,500	174,000	2,790,500	182,000	6	89	6	0			0.577	0.577
Slovakia	5,006,000	3,000,000	200,000	1,806,000	60	4	36	0			0.919	0.919
Slovenia	1,783,000	0	1,279,000	504,000	0	72	28				0.8462	0.8462
South Africa	9,058,000	9,058,000	0	0	100	0	0	0			0.1509	0.1509
Sri Lanka	3,878,600	2,883,600			74	0	0	995,000	210,000	700,000	0.1751	0.1301
Sudan	1,940,000	1,940,000			100	0	0				0.0432	0.0432
Sweden	16,562,750	1,666,000	4,687,000	10,209,750	10	28	62	0			1.5902	1.5902
Syria	125,000							125,000	125,000	0	0.0068	
Tanzania	300,000	0	0	0	0	0	0	300,000	200,000	100,000	0.0049	0
Thailand	3,595,421							0			0.0514	0.0514
Togo	149,500							149,500	149,500	0	0.0176	

Country	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
Tunisia	3,028,200	3,028,200	0	0	100	0	0	0			0.2537	0.2537
Uganda	250,000							250,000	150,000	100,000	0.0053	
Ukraine	8,623,000	3,434,500	5,188,500	0	40	60	0	0			0.1968	0.1968
United Kingdom	76,825,750	919,300	34,290,300	41,616,150	1	45	54	0			1.1411	1.1411
United States of America	510,000,000	28,000,000	241,000,000	241,000,000	5	47	47				1.5366	1.5366
Uruguay	1,736,000	1,736,000	0	0	100	0	0	0			0.4981	0.4981
Uzbekistan	7,304,500	5,559,000			76	0	0	1,745,500	1,145,500	600,000	0.2092	0.1592
Venezuela	3,386,500	625,500			18	0	0	2,761,000	2,461,000	300,000	0.118	0.0218
Vietnam	4,248,700	4,112,450	0	0	97	0	0	136,250			0.0433	0.0419
Zambia	325,000							325,000	225,000	100,000	0.0172	
Zimbabwe	307,000							307,000	60,000	247,000	0.0203	
TOTAL	**1,663,675,681**	**495,888,039**	**556,639,228**	**550,552,745**				**28,110,100**	**12,223,500**	**13,698,750**		

** 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 2021**

(82 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)	Total WFH Hemlibra donations (mg)
Argentina	43	6		
Armenia	15	13	2,142	64,260
Australia	44	308	681,240	
Austria	8	15		
Bahamas	0	1	0	
Bahrain	4	3	195,000	
Bangladesh				117,180
Benin	7	4	0	40,350
Bolivia		2		
Botswana	1	0	450	
Brazil	77		65,400	
Burkina Faso	1	26	0	52,920
Cambodia	5	30		90,720
Cameroon		18	0	75,600
Canada	87	46	778,575	
Chile	14		43,500	
Colombia	82	6	383,672	
Congo, Republic of the	2	3	0	15120
Costa Rica	15	2	12,315	
Côte d'Ivoire	2	31	74,760	
Croatia	12	15		
Cuba	12	7	30,030	
Czech Republic	15	24	151,916	
Egypt	450		400	
Estonia			32	
Finland	12	10	3,218,220	
France	104	318	2,790,885	
Georgia	5	2	240,000	
Germany			1,037,102	
Ghana	0	37	0	60,480

Country	Number of patients with inhibitors treated with Hemlibra	Number of patients without inhibitors treated with Hemlibra	Total Hemlibra purchased (mg)	Total WFH Hemlibra donations (mg)
Honduras	5	0		30,240
Hong Kong	5	9		
Hungary	12			
Iraq	20	0	0	
Ireland			543,540	
Israel	30	100		
Jamaica	10	12	0	90,420
Japan	73	512	5,336,175	
Kenya	20	14		165,870
Korea, Republic of			49,395	
Kuwait	5	5		
Kyrgyzstan	3			
Latvia			7,605	
Lebanon	2	0	32,400	
Lithuania	8	12	57,540	
Madagascar	3	14	0	41,580
Malaysia	18	0	4,000	
Maldives	1	1		
Mali	4	29	0	110,310
Mauritius		2	810	
Mexico	152	42	418,050	
Montenegro	1	1	6,840	
Morocco	0	12		
Mozambique				79,380
Nepal	14	47		400,680
Netherlands	19	190	1,133,310	
Nigeria	21	27	0	90,720
Pakistan	40	52	0	283,500
Panama	10		14,730	
Poland	50		212,235	
Portugal	28	3	88,290	
Romania			345	
Russia	130	209	15,609	
Saudi Arabia	46	36	125,760	

Country	Number of patients with inhibitors treated with Hemlibra	Number of patients without inhibitors treated with Hemlibra	Total Hemlibra purchased (mg)	Total WFH Hemlibra donations (mg)
Senegal	12	67	0	98,280
Serbia	13		52,680	
Singapore	7	12	30,015	
Slovakia	3	2	9,950	
Slovenia	3	18	100,000	
South Africa	20	4	58,845	
Sri Lanka	47	31		196,560
Sweden	18	0	85,035	
Tanzania	19	11	0	49,140
Thailand	7	4	7,860	
Uganda	8	14		34,020
Ukraine	24	8	157,710	
United Kingdom	140	801	3,497,110	
Uruguay	0		0	
Venezuela	38	21		150,000
Vietnam	35	33	0	
Zambia	0	11		37,830

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

(95 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)
Afghanistan				4	Precise	
Albania	12	Estimate		0	Precise	
Algeria			45,026			13,444,500
Argentina	55	Estimate		15	Estimate	5,700,000
Armenia			0			0
Australia	1	Estimate	16,566	2	Estimate	1,296,000
Bahamas	0	Precise	0	0	Precise	0
Bahrain	2	Precise	3,000	0	Precise	0
Barbados	2	Precise	0	2	Precise	0
Benin	0	Precise	0	0	Precise	0
Bolivia	0	Precise	0	2	Precise	0
Botswana	1	Precise		0	Precise	
Brazil	450	Precise	91,509	380	Precise	83,641,500
Burkina Faso	0	Precise	0	0	Precise	0
Cameroon	0	Precise	0	0	Precise	0
Canada	9	Estimate	14,149	4	Estimate	5,033,717
Chile	25	Estimate	3,398	12	Estimate	1,394,000
Colombia	33	Precise	39,600	17	Precise	13,382,000
Congo, Republic of the	0	Precise	0	0	Precise	0
Costa Rica			46,300,000			1,066,500
Côte d'Ivoire	0	Precise	0	4	Precise	0
Croatia	7	Precise		2	Precise	
Cuba	4	Precise	200	0	Precise	0
Czech Republic	6	Precise	2,103	0	Precise	0
Egypt	80	Estimate		20	Estimate	
El Salvador	13	Estimate		0	Estimate	
Eritrea	0	Precise	0	0	Precise	0
Estonia			14,150,000			
Ethiopia	0	Precise	0	0	Precise	0
Finland	5	Precise	483	0	Precise	724,000

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)
France	34	Precise	19,449,000	12	Precise	3,900,500
Georgia	2	Precise	545	2	Precise	315,000
Germany			17,215			2,741,000
Ghana	0	Precise	0	0	Precise	0
Honduras	9	Estimate		0	Precise	
Hungary	18	Precise				
India			25,000			
Iran	45	Estimate		25	Estimate	
Iraq	190	Precise	2	0	Precise	0
Ireland	4	Precise	2,189	2	Precise	75,000
Israel	10	Precise		2	Precise	
Jamaica	1	Precise	0	0	Precise	0
Japan			37,602			4,160,000
Kenya	10	Precise	43,200	20	Precise	0
Kuwait	4	Estimate		0	Estimate	
Kyrgyzstan	0	Precise		0	Precise	
Latvia	2	Estimate	1,008	1	Estimate	512,000
Lebanon	1	Precise		4	Precise	0
Lesotho				1	Precise	
Lithuania	7	Precise	772	1	Precise	318,000
Luxembourg	0	Precise	0	0	Precise	0
Madagascar	0	Precise	0	0	Precise	0
Malawi			0			0
Malaysia			1,214			540,000
Mali	0	Precise	0	0	Precise	0
Mauritius	0	Precise	450	0	Precise	0
Mexico			44,780			7,686,000
Montenegro	0	Precise	200	0	Precise	0
Morocco	51	Precise		1	Precise	
Netherlands			5,824			1,048,500
New Zealand	4	Precise		3	Precise	
Nigeria			0			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)
Norway	0	Precise		2	Precise	
Pakistan	0	Precise	0	2	Precise	35,000
Panama	0	Precise	177	0	Precise	200,500
Paraguay	2	Estimate		0	Precise	
Philippines	12	Estimate		9	Estimate	0
Poland			17,826			18,656,500
Portugal	13	Estimate	167,350,000	3	Estimate	1,699,000
Qatar	2	Precise		0	Precise	
Romania			5,496,000	94	Estimate	8,901,500
Russia			112,988			18,019,500
Saudi Arabia	85	Precise		35	Precise	
Senegal	0	Precise	0	0	Precise	0
Serbia	2	Precise	1,060	0	Precise	361,500
Singapore	1	Estimate	37	0	Precise	0
Slovakia	5	Precise	2,600	3	Precise	900,000
Slovenia	2	Precise	1,500	0	Precise	
South Africa			2,273			2,387,000
Sri Lanka			671			
Sudan			130,000	3	Estimate	7,500
Suriname	0	Precise	0	0	Precise	0
Sweden	2	Estimate	3,615	3	Estimate	2,772,500
Syria				0	Precise	0
Tanzania	0	Precise	0	0	Precise	0
Thailand	12	Precise	1,415	19	Precise	940,000
Trinidad and Tobago	2	Precise		5	Precise	
Tunisia	6	Precise	2,038	5	Precise	1,022,500
Uganda	1	Precise		0	Precise	
Ukraine			87,500,000			998,000
United Kingdom	113	Precise	46,851	19	Precise	10,665,500
Uruguay			1,000			113,000
Uzbekistan	29	Precise	234,600	29	Precise	195,500
Venezuela	27	Precise		0	Precise	
Vietnam	0	Precise	720	40	Precise	531,500

TABLE 20. **Use of VWD products 2021**

(55 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
Argentina	0		14	0		
Armenia	4	4	145	8	120	28
Australia	0	27	238	1	3	
Bahamas	0	0		0		0
Bahrain	0	250	30	0		250
Barbados		3				3
Benin				3		5
Botswana			2			
Brazil		168	1394			740
Cameroon						
Canada		79	269		2	86
Colombia	0	150	135	0	12	255
Côte d'Ivoire	0	2		1		3
Croatia		28	37			87
Cuba	11	14	0	0	0	3
Czech Republic	0	2	94	0		
France		52	125	2	24	
Ghana	0	0	0	0	0	0
Guyana	0	0		0		0
Honduras	0		0	0		
Hong Kong			1			
Hungary	0		232	0		
Iraq				0		
Jamaica	3		3			
Kenya	10	15	5	0	0	0
Latvia		19				
Lebanon			53			
Luxembourg	0	0	0	0	0	0
Madagascar				2		2

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
Malaysia	0	4	34	0		81
Mali	0	0	0	2		1
Mauritius						1
Montenegro	0	1	0	0		
Nepal				10		
Netherlands	0	223	491	0		
Nigeria					13	
Panama			537			537
Philippines	3					
Poland	0			0	0	
Portugal		95	145		2	60
Saudi Arabia	13	100	206	18	0	211
Senegal			8	10	4	13
Singapore	0		11	0	1	5
Slovakia			152			90
Slovenia			7	0		
Suriname			2			
Tanzania				5		5
Thailand	33	31	23	3		45
Trinidad and Tobago	1					1
Uganda	2					
United Kingdom			742		149	
Uruguay	0		3	0		
Uzbekistan			102		60	
Venezuela	10	150	69	0		480
Vietnam	83					61

A. National Hemophilia Organization

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

The WFH would like to know how you collect the data you are providing for this survey. If you have a registry, we would like to know more about the registry. A registry is a regularly updated centralized list of identified people with hemophilia (PWH) or inherited bleeding disorders. A registry includes information on demographics, 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 ☐ Patient organization ☐ Hospitals or clinics ☐ 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 ☐

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					☐

For each bleeding disorder, the sum of all Male, Female, and Sex Unknown should be equal to the Total.
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 ☐

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				
Age unknown				
No age data	☐	☐	☐	☐

The age distribution of Hemophilia A, B and unknown should be equal to the number of patients in 1. (If you do not know the age distribution, you can put that total number in the "Age unknown" box under the appropriate heading, hemophilia A, B or type unknown).
The age distribution of vWD should be equal to the number of vWD in question 2. (If you do not know the age distribution, you can put that total number in the VWD age unknown box)

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

6. 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	No Data	Number of type 3 VWD patients receiving replacement therapy	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 2021. (Patients who do not respond to normal treatment.)

Type of hemophilia	Total number with active inhibitors	No data	New cases of inhibitors in 2021	No data
Hemophilia A		☐		☐
Hemophilia B		☐		☐

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	☐		☐
Tranexamic 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 2021				☐

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 2021				☐

[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, 2021)

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				☐

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).

Hemophilia Comprehensive Care Centres 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?	
What percentage of the hemophilia patients in your country has access to a hemophilia treatment centre:	

Prophylaxis is regular, long-term treatment with a hemostatic agent 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.

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 **started** 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 ☐

D. The Cost and Use of Treatment

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 2021 (excluding donated factor)?		☐		☐
Plasma derived: How many international units of **plasma-derived** concentrates were used in your country in 2021 (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 2021 (excluding donated factor)?		☐		☐
Recombinant, extended half-life: How many international units of **recombinant** concentrates**, extended half-life** were used in your country in 2021 (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 2021?		☐		☐

18 C. Annual usage of purchased Hemlibra (Emicizumab)	Amount (mg)	Not known
How many milligrams (mg) of Hemlibra were purchased in your country in 2021? (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 2021? (excluding donated product)	**(mg)**	☐
How many international units (IU) of FEIBA were purchased in your country in 2021? (excluding donated product)	**(ui)**	☐

19. Gene Therapy	In 2021	Not known	Anytime	Not known
How many people in your country have received gene therapy?		☐		☐
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 ☐

20. Factor VIII Concentrates used in 2021

(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.

21. Factor IX Concentrates used in 2021

(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.

22. Prothrombin Complex Concentrates used in 2021
(Please check the box on the left if a product is used, and if known, fill out the cost per international unit in your currency.)

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

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

23. Other Products used in 2021
(Please check the box on the left if a product is used, and if known, fill out the cost per international unit in your currency.)

Used	Brand Name	Manufacturer	Price per IU
☐	Aryoseven	Aryogen	
☐	Byclot (1.5mg)	Kaketusken	
☐	Ceprotin	Baxalta (now part of Shire)	
☐	Clottafact Wilstart	LFB	
☐	Clottagen (fibrinogen)	LFB	
☐	Coagdex	Bio products	
☐	Coagil 7 (activated factor VII)	Pharmstandard	Price per vial: Vial size:
☐	Eqwilate	Octapharma	
☐	FACTEUR VII	LFB	
☐	Factor VII	Baxalta (now part of Shire)	
☐	Factor VII	Bio Products	
☐	Factor X P Behring	CSL Behring	
☐	Factor XI	Bio Products	
☐	FEIBA	Baxalta (now part of Shire)	
☐	Fibclot	LFB	
☐	Fibrinogen HT	Benesis	
☐	Fibrogammin P (=Fibrogammin HS) (Factor XIII)	CSL Behring	
☐	FIBRORAAS (fibrinogen)	Shanghai RAAS	
☐	Fibryga	Octapharma	
☐	Haemocomplettan P = Haemocomplettan HS (fibrinogen)	CSL Behring	
☐	HEMOLEVEN (Factor XI)	LFB	

☐	Kovaltry	Bayer	
☐	Minrin	Ferring	
☐	NovoSeven (=Niastase) (activated factor VII)	NovoNordisk	Price per vial: Vial size:
☐	Octaplas	Octapharma	
☐	Octostim	Ferring	
☐	Riastap	CSL Behring	
☐	Tretten rXIII	NovoNordisk	
☐	Veyvondi	Takeda	
☐	WILFACTIN (Von Willebrand Factor)	LFB	
☐	Other:		

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

24. Non-factor products used in 2021
(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.

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