

World Federation of Hemophilia Report on the ANNUAL GLOBAL SURVEY 2010

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All data are provisional.

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Introduction to the Report on the WFH Global Survey 2010

Report on the Annual Global Survey 2010 includes selected demographic and other data on people with hemophilia (PWH), von Willebrand disease (VWD), other rare factor deficiencies, and inherited platelet disorders throughout the world. The purpose of this report is to provide useful information to hemophilia organizations, hemophilia treatment centres (HTCs), and health officials involved in efforts to reduce or prevent complications of bleeding disorders in order to assist with program planning.

Methodology

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

Each year questionnaires are sent to national hemophilia associations linked with the WFH with the request that they in turn work with physicians or health officials, as necessary, to complete the survey. The WFH reviews completed questionnaires for inconsistencies, which are clarified where possible by communicating directly with the participating organization. The 2010 survey is the twelfth WFH survey. This report uses data for the years 2006, 2007, 2008, 2009 and 2010. Not all of our members are able to report every year. A list of participating countries and their data year can be found on page 11. The survey includes data on more than 250,000 people with hemophilia, von Willebrand disease and other bleeding disorders in 106 countries. Data from the WFH questionnaire are supplemented with data from other sources in order to provide a general socio-economic picture of each country surveyed. The survey questionnaire is included at the end of this report.

Comments on the graphs

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

Comments on data collection

Participation in the survey is voluntary. Although these data are self-reported, fairly consistent information on hemophilia care has been obtained from countries with similar economic capacities, validating its use for program planning. Countries that are part of the WFH's Global Alliance for Progress (GAP) program (Azerbaijan, Belarus, Ecuador, Jordan, Lebanon, Mexico, Russia, Thailand, Tunisia, China, and Syria) report more frequently than once per year, in cases where a 2010 survey form was not completed other WFH data was used. Some countries are only able to provide detailed data on gender, age, inhibitors and HIV/HCV infection for a limited subset of patients, for example they may know the total number of people with hemophilia in the country but have age and gender data from just one treatment centre. This report provides information on the annual usage of treatment products for 2010 only. It includes only those countries where the national hemophilia organization provided information. Quantities reported used were not independently verified except when the WFH has data on humanitarian donations in 2010. The amounts reported may only be factor bought through government or other sources. Not all national hemophilia organizations are able to report on all product used in their country.



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

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

2010 WFH Global Survey summary**Demographics**

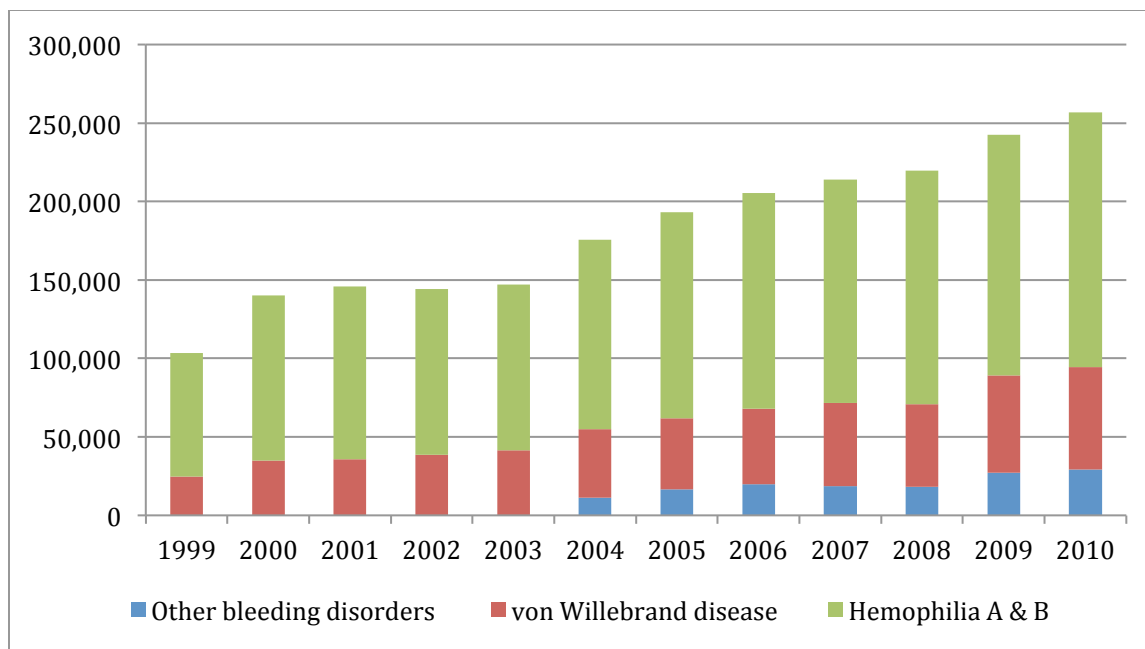
Number of countries in this survey	106
Percentage of world population covered by countries in 2010 survey report	93.5%
Number of people identified with hemophilia A and B	162,781
Number of people identified with VWD	65,100
Number of people identified with other bleeding disorders	29,301
Total number of people with bleeding disorders identified	257,182
Number of people with hemophilia A	125,049
Number of people with hemophilia B	25,160
Number of hemophilia A patients with clinically identified inhibitors	4554
Number of hemophilia B patients with clinically identified inhibitors	304

Factor usage

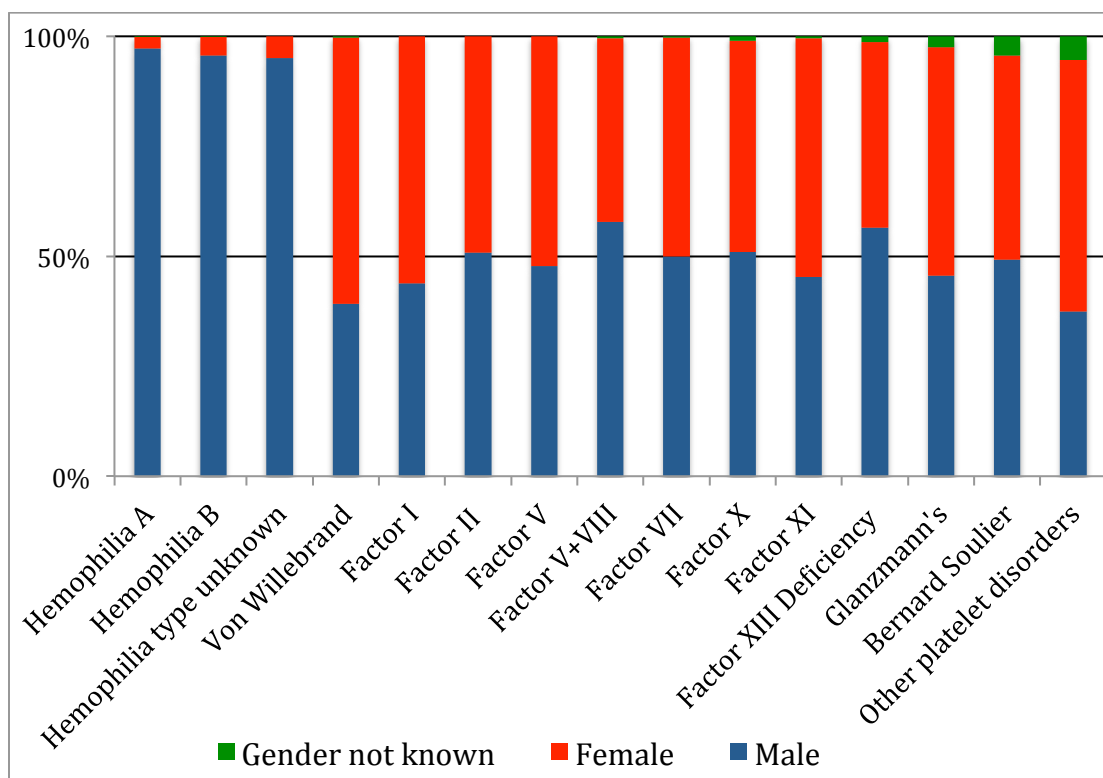
Mean global per capita factor VIII usage	1.42 IU	<i>61 countries reporting</i>
Median global per capita factor VIII usage	0.86 IU	<i>61 countries reporting</i>
Mean global per capita factor IX usage	0.24 IU	<i>52 countries reporting</i>
Median global per capita factor IX usage	0.18 IU	<i>52 countries reporting</i>
Total reported annual global consumption of factor VIII concentrates	6,013,837,683 IU	<i>61 countries reporting</i>
Total reported annual global consumption of factor IX concentrates	867,946,860 IU	<i>52 countries reporting</i>

(Please note that the group of countries reporting factor usage changes from year to year. The average per capita and total consumption figures reported this year cannot be directly compared to other survey years.)

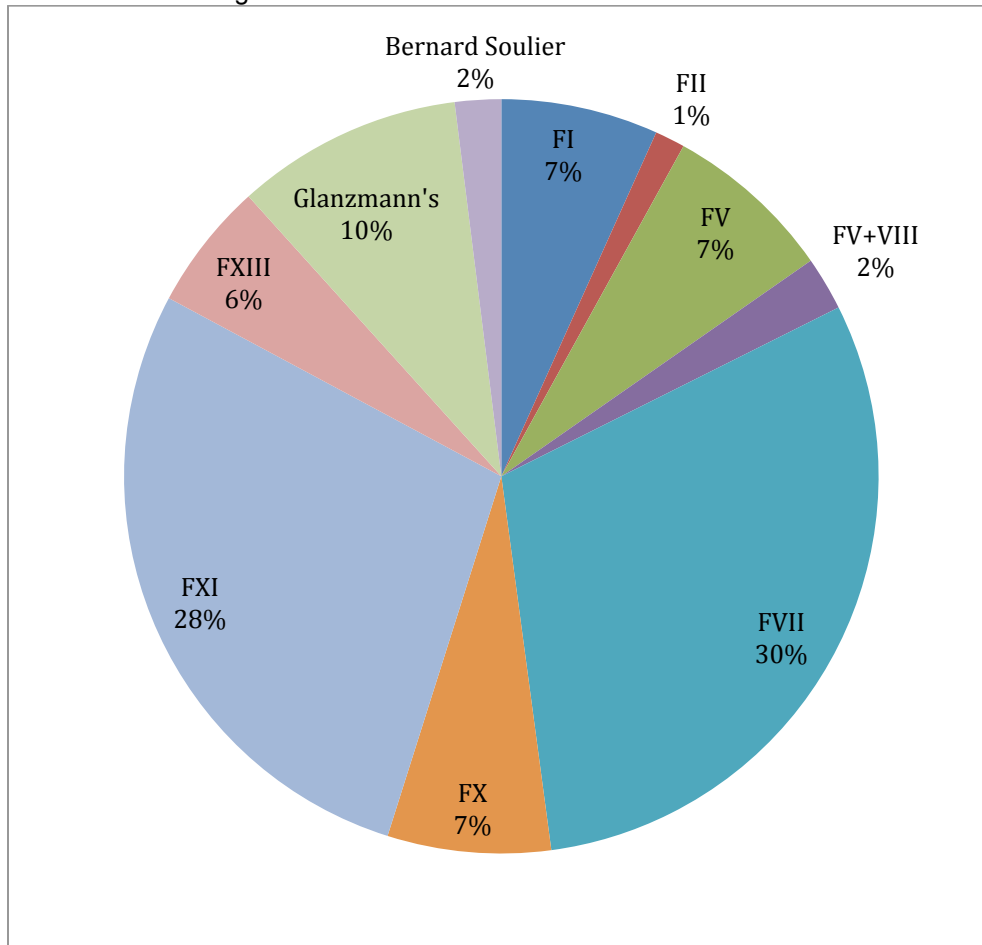
A. Identified patients – all disorders (Collection of data on other bleeding disorders began in 2004. The other disorders can be seen on graph C.)



B. The graph below shows the proportion of male and female patients for the all bleeding disorders. (See gender data on page 18.) These data are from the countries that provided gender distributions for 2010 or 2009 (81 reported for hemophilia, 71 reported for VWD and 61 reported for rare bleeding disorders).

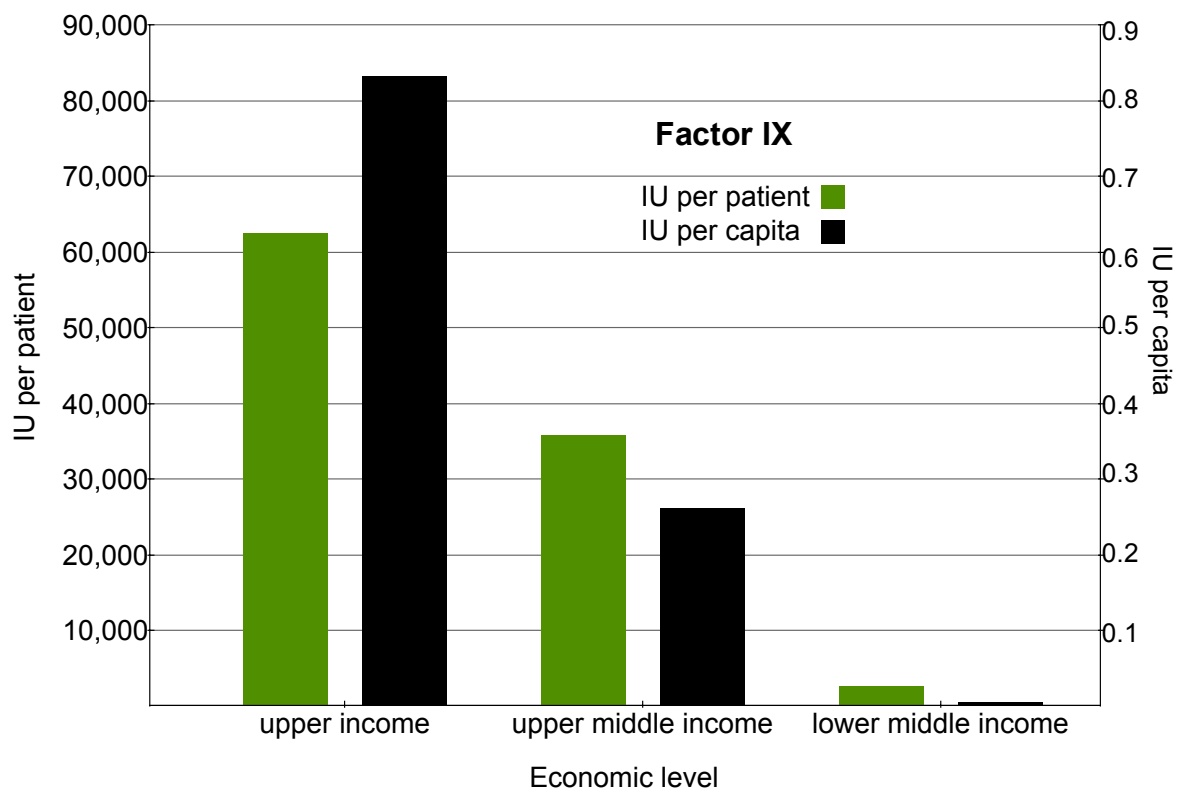
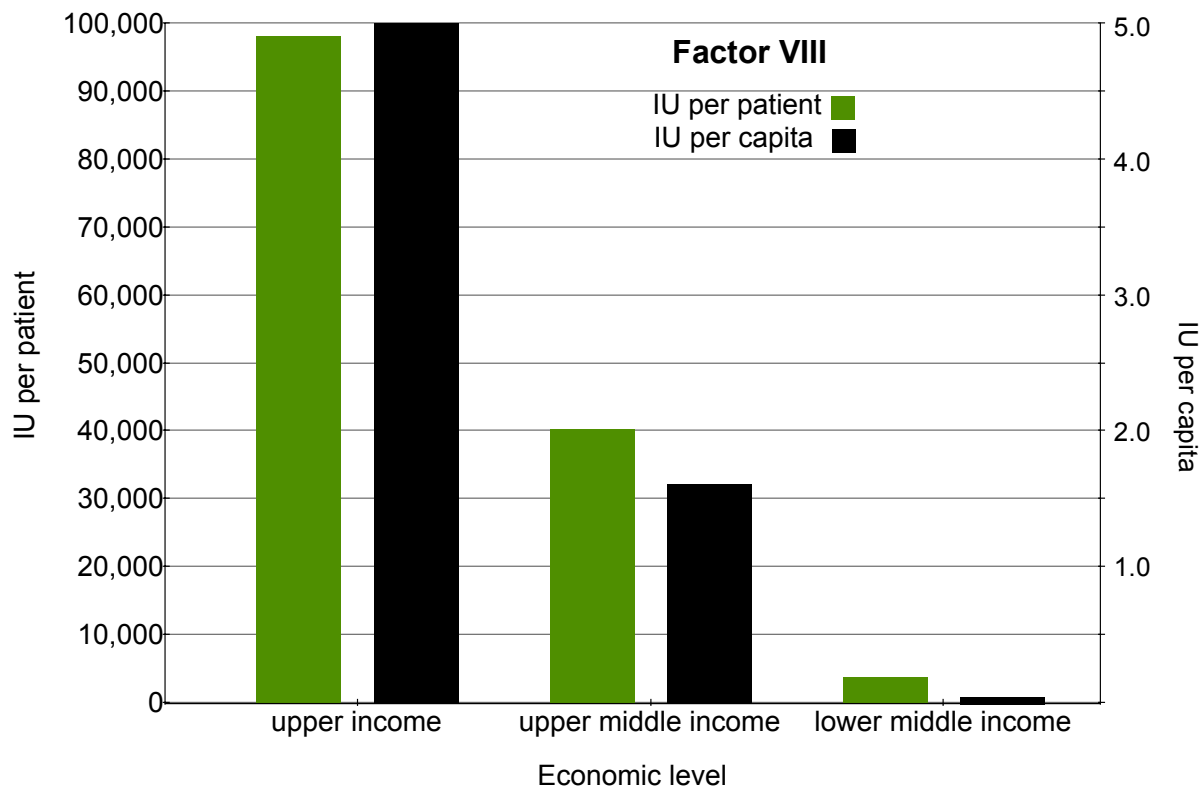


C. Distribution of other bleeding disorders

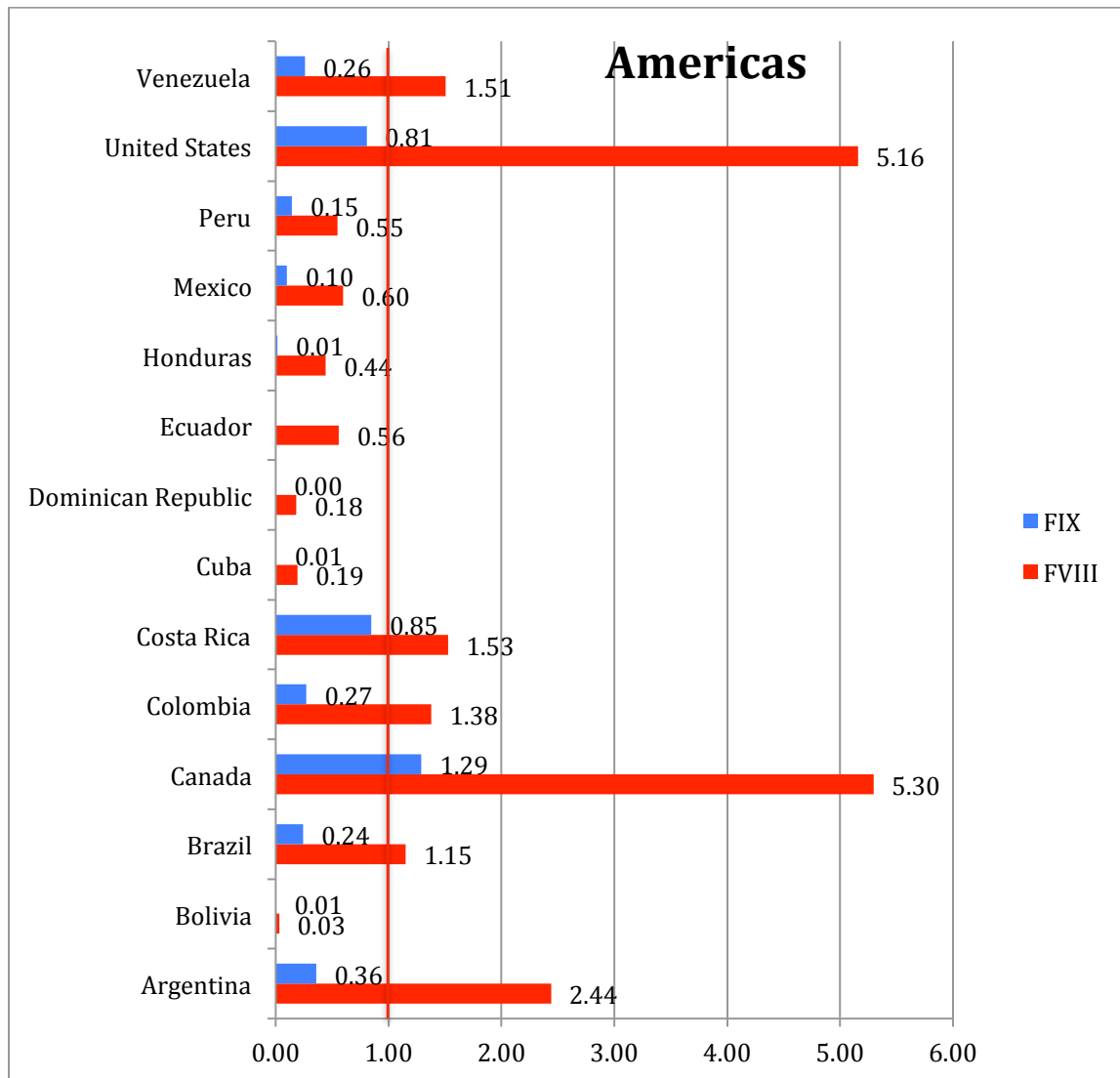


Many countries report significant numbers of patients with other platelet disorders but these have not been included in this graph. For the complete numbers, see the table starting on page 15.

D. Mean global factor use based on World Bank rankings. Categories are based on the rankings for 2010. (GNI in US dollars: lower middle income, \$996 - \$3,945; upper middle income, \$3,946 - \$12,195; and high income, \$12,196 or more.)

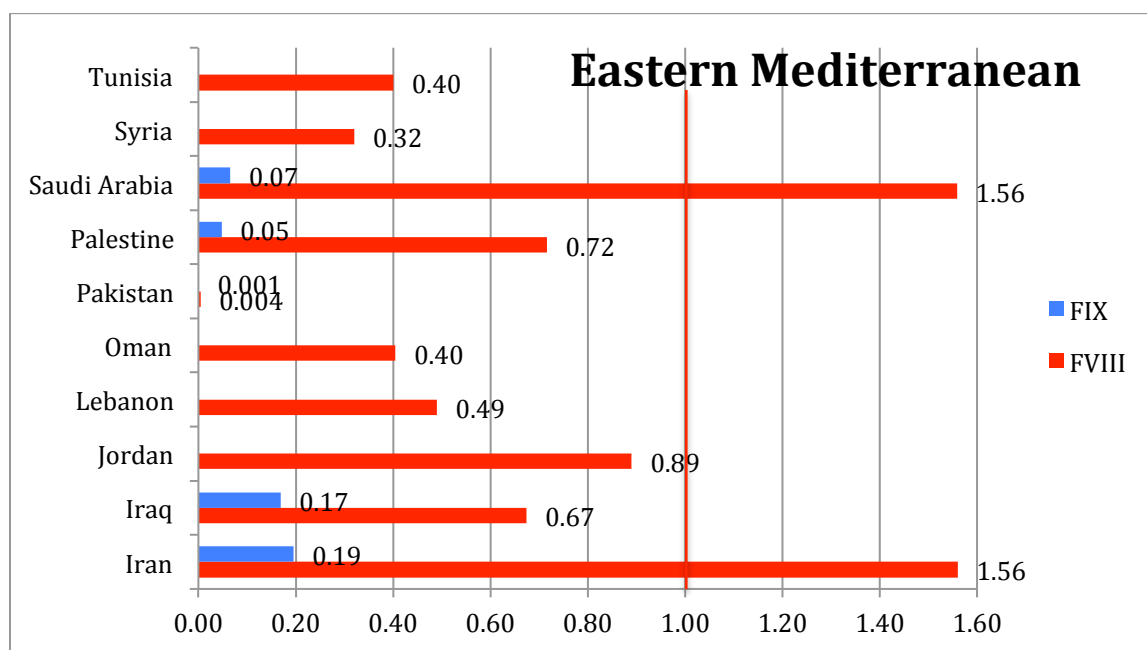
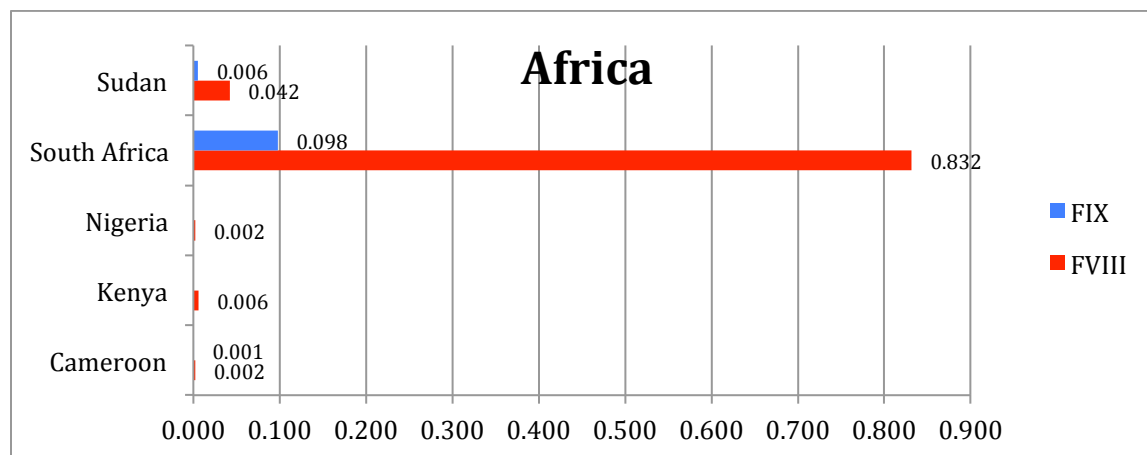


E. Mean per capita factor use in 2010 – regional comparisons of IU/total population.



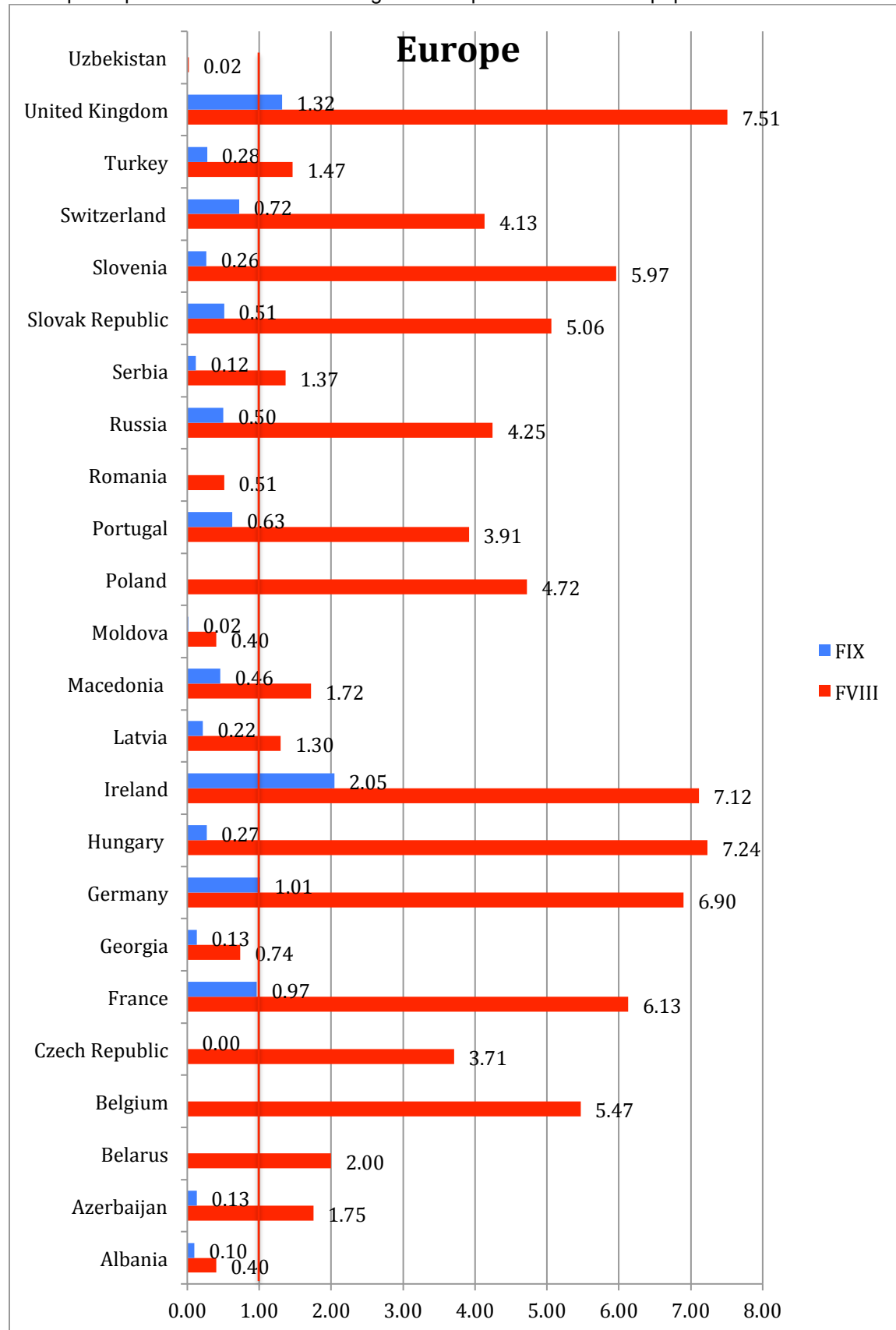
PLEASE NOTE: The X axis showing the number of IU/capita is different in each graph. The red line indicates 1 IU per capita of factor VIII. The WFH has established that one international unit (IU) of FVIII clotting factor concentrate per capita should be the target minimum for countries wishing to achieve optimal survival for the hemophilia population. In regions where the per capita level is lower than 1, there is no red line. Higher levels would be required to preserve joint function or achieve a quality of life equivalent to an individual without hemophilia. Please note the red line does not apply to factor IX.

Mean per capita factor use in 2010 – regional comparisons of IU/total population.

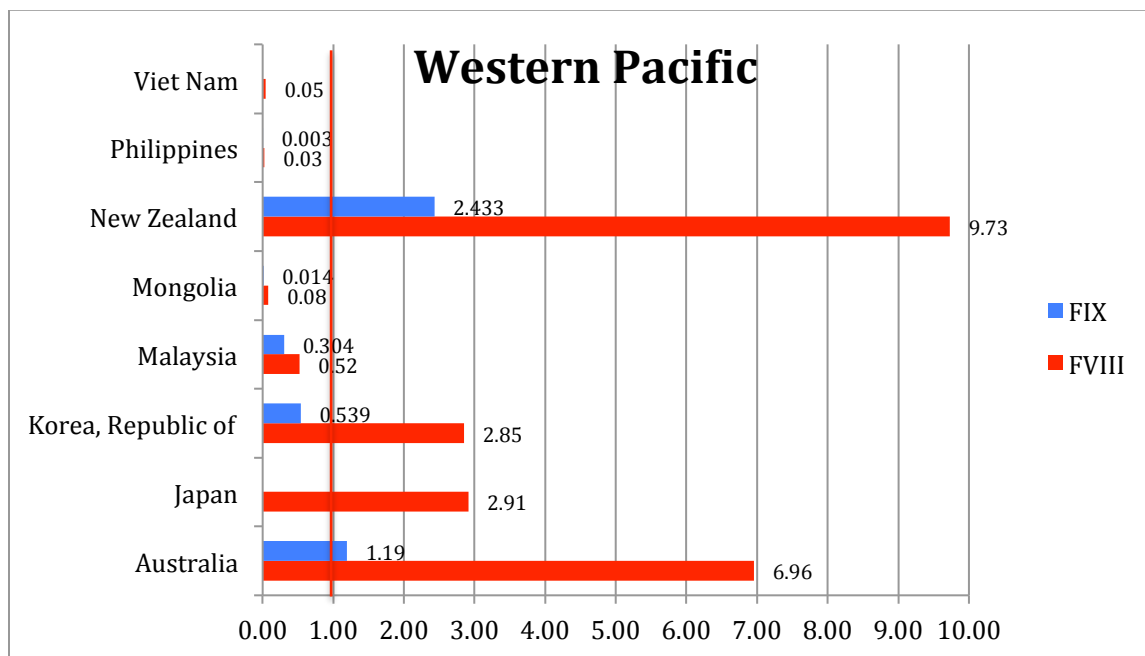
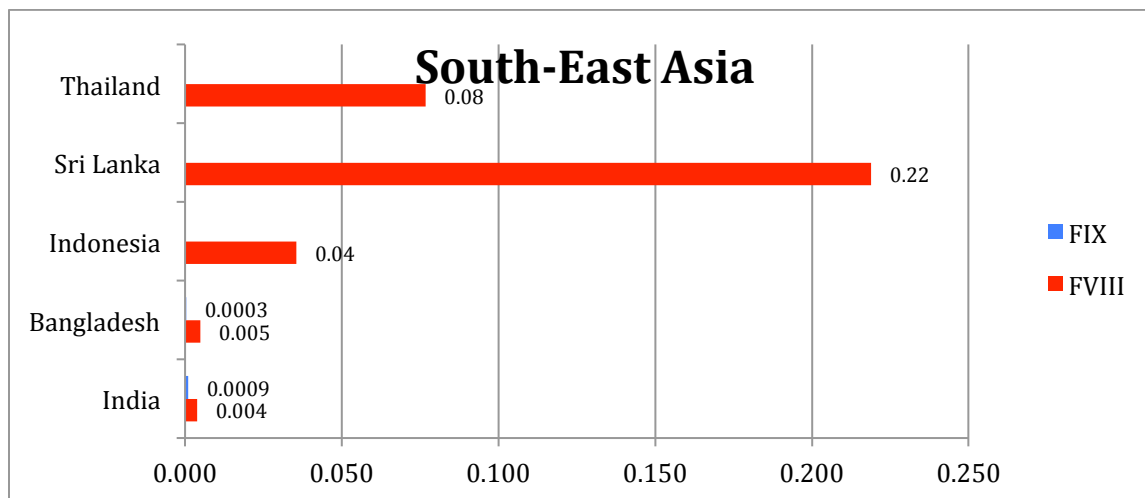


PLEASE NOTE: The X axis showing the number of IU/capita is different in each graph. The red line indicates 1 IU per capita of factor VIII. The WFH has established that one international unit (IU) of FVIII clotting factor concentrate per capita should be the target minimum for countries wishing to achieve optimal 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 red line does not apply to factor IX.

Mean per capita factor use in 2010 – regional comparisons of IU/total population.



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Countries included in the 2010 WFH Global Survey Report

(Please note: the year indicates the year the submitted data applies to. Not all of our members are able to submit data every year. For the 2010 survey report, 75 countries submitted data for 2010. The data used from other years is as follows. 2009: 18 countries, 2008: 5 countries, 2007: 5 countries, 2006: 3 countries.)

Albania	2010	Germany	2010	Palestine	2010
Algeria	2010	Greece	2009	Panama	2009
Argentina	2010	Guatemala	2010	Paraguay	2009
Armenia	2009	Honduras	2010	Peru	2010
Australia	2010	Hungary	2010	Philippines	2010
Austria	2009	Iceland	2007	Poland	2010
Azerbaijan	2010	India	2010	Portugal	2010
Bahrain	2007	Indonesia	2010	Qatar	2006
Bangladesh	2010	Iran	2010	Romania	2010
Belarus	2009*	Iraq	2010	Russia	2010
Belgium	2010	Ireland	2010	Saudi Arabia	2010
Belize	2009	Israel	2010	Senegal	2010
Bolivia	2010	Italy	2007	Serbia	2010
Bosnia-Herzegovina	2006	Japan	2010	Singapore	2006
Brazil	2010	Jordan	2010	Slovak Republic	2010
Bulgaria	2009	Kazakhstan	2008	Slovenia	2010
Cambodia	2010	Kenya	2010	South Africa	2010
Cameroon	2010	Korea, Republic of	2010	Spain	2010
Canada	2010	Kyrgyzstan	2010	Sri Lanka	2010
Chile	2009	Latvia	2010	Sudan	2010
China	2010	Lebanon	2008*	Sweden	2009
Colombia	2010	Lesotho	2009	Switzerland	2010
Costa Rica	2010	Lithuania	2009	Syria	2009*
Cote d'Ivoire	2010	Macedonia	2010	Thailand	2010
Croatia	2007	Malaysia	2010	Tunisia	2008*
Cuba	2010	Mexico	2010	Turkey	2010
Czech Republic	2010	Moldova	2010	Ukraine	2007
Denmark	2010	Mongolia	2010	United Kingdom	2010
Dominican Republic	2010	Nepal	2010	United States	2010
Ecuador	2009*	Netherlands	2009	Uruguay	2009
Egypt	2009	New Zealand	2010	Uzbekistan	2010
Eritrea	2010	Nicaragua	2009	Venezuela	2010
Ethiopia	2010	Nigeria	2010	Viet Nam	2010
Finland	2010	Norway	2008	Zimbabwe	2008
France	2010	Oman	2010		
Georgia	2010	Pakistan	2010		

* For countries that did not complete a 2010 survey form but are part of the WFH GAP program, WFH data on the total number of patients identified and factor use in 2010 was used. All other data are from the year indicated.

**Population statistics**

(NOTE: In all of the population charts a 0 indicates that the member organization reported the number zero, a blank space indicates that no number was reported.)

Country	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Albania	2,986,952	250		
Algeria	34,586,184			
Argentina	41,343,201	2,264	355	
Armenia	2,966,802	208	10	10
Australia	21,515,754	2,390	1,748	542
Austria	8,214,160	509		
Azerbaijan	8,303,512	885	138	
Bahrain	738,004	20		4
Bangladesh	156,118,464	503	0	8
Belarus	9,612,632	745	171	45
Belgium	10,423,493	988	1,338	133
Belize	314,522	14		
Bolivia	9,947,418			
Bosnia-Herzegovina	4,621,598	140	30	
Brazil	201,103,330	10,065	4,480	1,649
Bulgaria	7,148,785	589	79	38
Cambodia	14,453,680	65	1	2
Cameroon	19,294,149	96	1	0
Canada	33,759,742	3,380	3,563	1,460
Chile	16,746,491	1,252		
China	1,330,141,295	8,590	44	181
Colombia	44,205,293	1,915	208	138
Costa Rica	4,516,220	194	58	22
Cote d'Ivoire	21,058,798	55	2	7
Croatia	4,486,881	477	282	139
Cuba	11,477,459	403	110	1,800
Czech Republic	10,201,707	833		
Denmark	5,515,575	481	391	87
Dominican Republic	9,823,821	249	71	121
Ecuador	14,790,608	251	35	13
Egypt	80,471,869	5,307	455	986
Eritrea	5,792,984	56	1	
Ethiopia	88,013,491	44	17	
Finland	5,255,068	428	3,004	33
France	64,768,389	5,478	1,186	346

Country	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Georgia	4,600,825	256	22	10
Germany	82,282,988	4,654	4,447	
Greece	10,749,943	890	684	215
Guatemala	13,550,440	114	18	2
Honduras	7,989,415	283	11	3
Hungary	9,992,339	999	1,318	375
Iceland	308,910	64	96	
India	1,173,108,018	13,993	477	422
Indonesia	242,968,342	1,388		
Iran	76,923,300	5,069	877	1,977
Iraq	29,671,605	902	182	201
Ireland	4,622,917	730	975	1,316
Israel	7,353,985	540	4	1
Italy	58,090,681	3,270	1,650	700
Japan	126,804,433	5,346	944	502
Jordan	6,407,085	327	215	216
Kazakhstan	15,460,484	1,360	460	108
Kenya	40,046,566	150		
Korea, Republic of	48,636,068	1,867	90	90
Kyrgyzstan	5,508,626	320	10	
Latvia	2,217,969	140	101	2
Lebanon	4,125,247	175	63	37
Lesotho	1,919,552	15	1	0
Lithuania	3,545,319	152	149	43
Macedonia	2,072,086	315	90	6
Malaysia	28,274,729	1,188	464	346
Mexico	112,468,855	4,527	191	9
Moldova	4,317,483	243	4	
Mongolia	3,086,918	75	4	
Nepal	28,951,852	336	1	13
Netherlands	16,783,092	1,397	257	65
New Zealand	4,252,277	416	177	29
Nicaragua	5,995,928	217	59	4
Nigeria	152,217,341	135	6	
Norway	4,676,305	397	858	37
Oman	2,967,717	97	281	271
Pakistan	184,404,791	1,436	308	270

Country	Population	People with hemophilia	People with von Willebrand disease	People with other bleeding disorders
Palestine	2,514,845	135	10	63
Panama	3,410,676	262	346	16
Paraguay	6,375,830	448	1	1
Peru	29,907,003	743	144	17
Philippines	99,900,177	1,081	29	
Poland	38,463,689	2,653	1,202	629
Portugal	10,735,765	632	48	21
Qatar	840,926	112	7	62
Romania	21,959,278	1,662	350	9
Russia	139,390,205	5,421	1,254	954
Saudi Arabia	25,731,776	326	75	36
Senegal	12,323,252	136	1	7
Serbia	7,344,847	445	189	18
Singapore	4,701,069	204	58	85
Slovak Republic	5,470,306	561	506	855
Slovenia	2,003,136	203	154	98
South Africa	49,109,107	1,886	579	217
Spain	46,505,963	1,925	702	292
Sri Lanka	21,513,990	664		
Sudan	43,939,598	650	156	120
Sweden	9,074,055	1,020	1,538	
Switzerland	7,623,438	697	133	70
Syria	22,198,110	465	30	16
Thailand	67,089,500	1,039	69	53
Tunisia	10,589,025	375	76	112
Turkey	77,804,122	3,914	574	596
Ukraine	45,415,596	2,600		
United Kingdom	62,348,447	6,573	9,187	7,218
United States	310,232,863	17,485	13,239	1,772
Uruguay	3,510,386	236	316	11
Uzbekistan	27,865,738	1,155	88	33
Venezuela	27,223,228	2,040	707	670
Viet Nam	89,571,130	1,815	57	216
Zimbabwe	11,651,858	311	3	
Total	6,176,411,696	162,781	65,100	29,301

Distribution of reported bleeding disorders by country

(NOTE: In all of the population charts a 0 indicates that the member organization reported the number zero, a blank space indicates that no number was reported.)

Country	Hemophilia A	Hemophilia B	Hemophilia type unknown	VWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXIII	Bleeding Dis.: Type Unknown	Glanzmann's.	Bernard Soulier	Platelet disorders: Other/Unknown
Albania	232	18							2							
Algeria																
Argentina	1,849	257	158	356												23
Armenia	184	18		10	5				2	2	1			1		
Australia	1,927	463		1,748	15		13		48	10	126	16	140	7	1	146
Austria																
Azerbaijan	853	32		138			3	4	8	7	3	3		1	3	3
Bahrain	19	1							1	3				2	1	
Bangladesh	437	66	6	0	1							1				
Belarus	452	94		171					14	1	26	4				
Belgium	813	175		1,338		1	17			4	81	2	9	19		
Belize	9	5														
Bolivia																
Bosnia-Herzegovina	100	10		30												
Brazil	8,449	1,616		4,480	23	6	78	9	309	55	98	36	352	118	20	126
Bulgaria	531	58		79	7	1	1		6	3	2	2	83	10		9
Cambodia	57	8		1								1		1		2
Cameroon	90	5	0	1	0	0	0	0	0	0	0	0	0	0	0	0
Canada	2,722	658		3,563	78	11	50	4	246	21	322	51	80	53	28	553
Chile	1,068	184														
China	7,365	994		44	2		2		6		13	1				
Colombia	1,446	303	145	208	15	9	9	2	17	1	11	7	37	5	5	20
Costa Rica	165	29		58	1				8	4	5	4				
Cote d'Ivoire																
Croatia	385	92	0	282	6	0	12	3	48	3	19	7	3			17
Cuba	334	69		110	1	1	1	1	0	0	11	6	3	2	0	1,774
Czech Republic	719	114														
Denmark	388	93		391	1	1	2		4	8	4	9		9	11	38
Dominican Republic	216	33		71					5	22			90	3		1
Ecuador	437	50		79	1		1		2	1	3	1	5			
Egypt	129	37		25	8	1	4	1	4	12	1	4		20		
Eritrea	49	7		1												
Ethiopia	35	9	58	17												
Finland	332	96		3,004		2	5		7	4	2	13				

Country	Hemophilia A	Hemophilia B	Hemophilia type unknown	vWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXIII	Bleeding Dis.: Type Unknown	Gluzmann's.	Bernard Soulier	Platelet disorders: Other/Unknown
France	4,491	987	0	1,186	36	1	36	7	107	18	116	25				
Georgia	218	38	10	22					2			1				6
Germany	3,957	697		4,447												
Greece	750	140		684	16	1	6		56	7	46	10	1	13	7	52
Guatemala	108	6		18					1					1		
Honduras	199	19		11					1	1		1				
Hungary	792	207	0	1,318	13	1	14	0	206	15	61	1				
Iceland	63	2	0	96										0	12	
India	11,648	2,061	284	477	48	3	19	45	16	20	6	46		180	39	
Indonesia	334	48	1,006													
Iran	4,187	882		877	96		115	162	330	130	102	174	66	388	64	306
Iraq	676	226		182	34	1	1	1	53	11	1	16				83
Ireland	514	216	0	975	0	0	86	0	74	93	145	7	658	11	3	239
Israel	458	92		21												
Italy	2,697	573	21	1,650	49	14	73	23	308	54	156	21	45			115
Japan	4,394	952		944	58	6	26	7	54	15	26	23				
Jordan	249	78		215		4	11		40	21	36	10		93	1	
Kazakhstan	1,036	324		460												
Kenya	120	13														
Korea, Republic of	1,522	345		90	6	0	4	8	26	1	13	5	19			
Kyrgyzstan	209	17	84	10										5	2	
Latvia	140	25		101	0	0	0	0	2	0	0	0	0			
Lebanon	109	29		62	21	1	4	1	1	1	3	2				3
Lesotho	15	0	0	1	0											
Lithuania	130	22	0	149	0	0	2	0	35	0	1	3				11
Macedonia	211	104		90							1	1				
Malaysia	1,008	180		464	4	2	18	1	43	14	40	13		42	0	35
Mexico	3,582	576	369	191			2		5	1				1		
Moldova	227	14		4					1							
Mongolia	62	13		4												
Nepal	298	40		1					1	9		1				
Netherlands	1,195	202														
New Zealand	341	75	0	177	0	0	0	0	4	1	5	0	14	0	0	4
Nicaragua	191	28		57	4											1
Nigeria	129	6	1	6												
Norway	301	96	0		3		2	0	23	0	0					
Oman	90	7		281	5	1	6	5	48	3	17	1	8	24	2	151
Pakistan	1,213	216	7	308	7	0	20	5	24	24	2	29	42	76	11	18
Palestine	107	28		10	12		2			11				36	2	

Country	Hemophilia A	Hemophilia B	Hemophilia type unknown	vWD	FI	FII	FV	FV+VIII	FVII	FX	FXI	FXIII	Bleeding Dis.: Type Unknown	Glanzmann's.	Bernard Soulier	Platelet disorders: Other/Unknown
Panama	237	25		346		1			3	10					1	1
Paraguay	434	14		1					1							
Peru	577	103	63	144	0	0	1	0	8	0	5	1	0	1	0	0
Philippines	919	137	42	29												
Poland	2,216	389	0	1,199	50	0	20	3	193	16	33	10	51	17	2	46
Portugal	522	110		48	2		3			1	7	1	43	1		6
Qatar	87	25		7	2		6	1	6	2	20	1				
Romania	1,443	204	15	350		1		2	5		1					
Russia	4,720	701		1,254									954			
Saudi Arabia	260	66	0	75	0	2	3	1	6	1	9	13	0	66	2	0
Senegal	129	7		1			1		3							1
Serbia	381	64		189	1			1	6		5	4			1	
Singapore	176	28	0	58	0	0	15	0	9	0	46	3				
Slovak Republic	489	74		506	66		48	2	553	18	36	3		10	6	22
Slovenia	182	21		154			9	2	11		14	1		3		
South Africa	1,585	301		579	7	0	43	5	18	10	28	7		16	23	52
Spain	1,655	270		702	15	3	12	3	21	9	24	20	171	15		
Sri Lanka	498	137	29													
Sudan	558	92	0	156	9	1	20	0	4	9	0	17	0			60
Sweden																
Switzerland	582	115		133	11	0	0	4	29	4	8	14				
Syria	252	48		30	5		2	3	2	1				3		
Thailand	927	112		69	1	0	2	1	12	1	0	0	0			
Tunisia	162	38	0	76	11	0	3	5	15	1	4	13		138	6	
Turkey	3,294	620		574			20		257	74	7	40	186			5
Ukraine																
United Kingdom	5,420	1,153		9,187	175	10	132	23	679	183	1,918	59		109	58	1,306
United States	13,276	4,209		13,239	123	48	163		730	89	504	115				
Uruguay	185	30	21	316	1		2		3	1	2		2	1	1	
Uzbekistan	1,032	117		88		7			3				33	5	1	
Venezuela	1,613	436		741	43	66	38	24	148	91	380	13		15	10	71
Viet Nam	1,475	336	4	57	1	3	1	6	15	9	4	1	37	63		71
Zimbabwe																
Total	125,049	25,160	2,323	62,102	1099	210	1189	375	4938	1141	4560	894	3132	1584	323	5377

Gender distributions

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

Disorder	Total patients identified	Male	Female	Gender not known
Hemophilia A (81 countries reporting)	96,691	94,095	2494	102
Hemophilia B (81 countries reporting)	20,149	19,269	852	28
Hemophilia type unknown (81 countries reporting)	1,011	961	50	0
Von Willebrand Disorder (64 countries reporting)	50,274	19,727	30,382	165
Factor I Deficiency (62 countries reporting)	913	401	512	0
Factor II Deficiency (62 countries reporting)	116	59	57	0
Factor V Deficiency (62 countries reporting)	1000	478	522	0
Factor V+VIII Deficiency (62 countries reporting)	273	158	114	1
Factor VII Deficiency (62 countries reporting)	4,116	2,058	2,049	9
Factor X Deficiency (62 countries reporting)	937	478	449	10
Factor XI Deficiency (62 countries reporting)	3,838	1,740	2,082	16
Factor XIII Deficiency (62 countries reporting)	771	436	325	10
Bleeding Disorder: Type Unknown (62)	2,097	863	900	291
Platelet disorders: Glanzmanns thrombasthenia (62)	1,245	568	647	30
Platelet disorders: Bernard Soulier Syndrome (62)	254	125	118	11
Platelet disorders: other or unknown (62)	5,318	2,000	3,062	256

Patients with current clinically significant inhibitors (Patients who do not respond to standard treatment.)

Country	Hemophilia A	Hemophilia A w/ clinically identified inhibitors	%	Hemophilia B	Hemophilia B w/ clinically identified inhibitors	%
Argentina	1,849	281	15	257	8	3
Armenia	184	7	4	18	1	6
Australia	1,927	137	7	463	6	1
Austria		15	NA		1	NA
Azerbaijan	853	12	1	32		0
Brazil	8,449	642	8	1,616	30	2
Bulgaria	531	16	3	58	1	2
Cameroon	90	5	6	5	0	0
Canada	2,722	80	3	658	5	1
Chile	1,068	31	3	184	1	1
China	7,365	24	0	994	1	0
Colombia	1,446	54	4	303	6	2
Costa Rica	165	17	10	29	0	0
Cote d'Ivoire		10	NA		1	NA
Cuba	334	61	18	69	0	0
Czech Republic	719	16	2	114	1	1
Denmark	388	9	2	93	1	1
Dominican Republic	216	1	0	33		0
Finland	332	43	13	96	1	1
France	4,491	107	2	987	4	0
Georgia	218	1	0	38		0
Germany	3,957	68	2	697	12	2
Greece	750	20	3	140	2	1
Guatemala	108	2	2	6		0
Honduras	199	1	1	19		0
Hungary	792	36	5	207	1	0
Iceland	63	0	0	2	0	0
Indonesia	334	65	19	48		0
Iran	4,187	223	5	882	6	1
Iraq	676	14	2	226	1	0
Ireland	514	10	2	216	1	0
Italy	2,697	288	11	573	8	1
Japan	4,394	78	2	952	16	2
Jordan	249	18	7	78	1	1
Kazakhstan	1,036	5	0	324	2	1
Latvia	140	2	1	25	2	8

Country	Hemophilia A	Hemophilia A w/ clinically identified inhibitors	%	Hemophilia B	Hemophilia B w/ clinically identified inhibitors	%
Lebanon	109	3	3	29	0	0
Lesotho	15	0	0	0	0	NA
Lithuania	130	8	6	22	0	0
Macedonia	211	2	1	104	1	1
Malaysia	1,008	87	9	180	2	1
Mexico	3,582	169	5	576	10	2
New Zealand	341	13	4	75	0	0
Nicaragua	191	1	1	28		0
Norway	301	12	4	96	0	0
Oman	90	12	13	7	0	0
Pakistan	1,213	50	4	216	4	2
Panama	237	12	5	25	0	0
Peru	577	7	1	103	1	1
Philippines	919	9	1	137	1	1
Poland	2,216	156	7	389	3	1
Romania	1,443	102	7	204	3	1
Saudi Arabia	260	23	9	66	0	0
Senegal	129	10	8	7		0
Serbia	381	16	4	64	0	0
Singapore	176	10	6	28	0	0
Slovak Republic	489	12	2	74	1	1
Slovenia	182	2	1	21	0	0
Spain	1,655	75	5	270	6	2
Sri Lanka	498	43	9	137		0
Sudan	558	12	2	92	1	1
Sweden		21	NA		5	NA
Switzerland	582	13	2	115	1	1
Syria	252	24	10	48	4	8
Tunisia	162	7	4	38	0	0
Turkey	3,294	61	2	620	10	2
U.K.	5,420	198	4	1,153	11	1
United States	13,276	738	6	4,209	69	2
Uruguay	185	3	2	30	1	3
Uzbekistan	1,032	73	7	117		0
Venezuela	1,613	82	5	436	2	0
Viet Nam	1,475	29	2	336	0	0
	98,531	4554	5	25,160	302	1

Age distribution: hemophilia A (73 countries reported age data)

Country	0-4	5-13	14-18	19-44	45+	Age not known
Albania	6	40	50	120	16	
Argentina	107	272	202	811	407	50
Armenia	5	20	27	120	11	
Australia	99	238	150	750	690	
Austria	10	72	51	202	108	
Azerbaijan	7	76	69	500	201	
Bangladesh	16	136	106	154	25	0
Belarus	8	66	21	357		
Belgium	29	109	68	275	324	8
Belize		7	1	1		
Brazil	376	1,570	1,074	4,120	1,253	56
Bulgaria	9	29	34	267	152	
Cambodia	19	25	6	6		
Cameroon	11	15	16	42	1	0
Canada	143	387	236	1,141	815	
Chile	24	173	145	475	206	45
China	489	1,623	807	3,491	955	
Colombia	26	130	131	472	136	551
Costa Rica	19	39	19	71	17	
Cote d'Ivoire	6	20	12	8	2	2
Cuba	13	43	44	189	45	0
Czech Republic	38	79	71	282	248	
Ecuador	27	103	45	174	51	37
Egypt	80	29	3	14		
Eritrea	3	15	4	19	3	5
Ethiopia	8	10	6	7	4	
France	271	732	447	1,923	1,118	0
Georgia	18	36	25	108	31	
Greece	16	87	44	310	293	
Guatemala	8	38	27	33	4	0
Hungary	27	78	50	358	279	
Iran	194	611	394	2,466	552	
Iraq	131	239	131	155	20	
Ireland	34	96	36	214	134	
Kenya	5	30	30	20	10	25
Korea, Republic of	71	239	192	803	217	
Kyrgyzstan			28	147	34	
Latvia	4	14	12	57	28	0

Country	0-4	5-13	14-18	19-44	45+	Age not known
Lesotho	0	3	4	4	0	
Lithuania	0	17	20	62	31	
Malaysia	235	212	50	77	25	409
Mexico	99	578	426	1,382	276	821
Moldova	4	21	20	114	68	
Mongolia	6	12	8	24	1	11
Nepal	39	103	42	112	11	
Netherlands	16	226	117	360	434	
New Zealand	29	53	31	126	70	42
Nicaragua	84		87	84	25	
Oman	16	32	12	29	1	
Pakistan	177	312	170	502	46	6
Palestine	15	33	30	20	9	
Panama	11	34	15	155	22	
Paraguay	29	65	82	190	68	
Peru	35	123	72	236	52	57
Philippines	33	246	164	327	54	95
Poland	44	174	151	1,209	693	
Portugal	12	57	26	235	145	47
Romania	4	99	111	685	475	69
Saudi Arabia	56	92	51	59	3	
Senegal	10	48	12	50	6	3
Serbia	21	46	44	160	110	
Slovak Republic	22	41	25	239	162	
Slovenia	5	17	6	96	58	
South Africa	80	265	158	714	368	45
Spain	39	157	89	787	452	131
Sri Lanka	43	149	38	26	5	237
Sudan	58	194	87	190	12	17
Switzerland	10	79	42	230	221	0
Syria	24	82	40	96	10	
Turkey	189	764	483	1,421	437	0
United Kingdom	279	702	461	2,113	1,862	3
Uruguay	15	40	15	47	30	40
Venezuela	104	187	287	582	288	
Total	4,200	12,789	8,290	33,405	14,920	2,812

Age distribution: hemophilia B (71 countries reported age data)

Country	0-4	5-13	14-18	19-44	45+	Age not known
Albania	1	4	4	7	2	
Argentina	12	46	33	107	50	9
Armenia	1	2	2	13		
Australia	15	66	27	203	152	
Austria	5	8	9	26	18	
Azerbaijan	1	4	5	6	16	
Bangladesh	2	24	23	15	2	0
Belgium	4	19	12	63	75	2
Belize		2	1	2		
Brazil	60	335	217	739	261	4
Bulgaria	1	2	3	35	10	
Cambodia	4	1	2	1		
Cameroon	3	1	1	0	0	0
Canada	30	65	72	280	211	
Chile	10	30	35	62	28	19
China	57	180	110	484	163	
Colombia	6	38	22	101	28	108
Costa Rica	3	4	5	17	0	
Cote d'Ivoire	1	2	1	1	0	0
Cuba	3	10	9	34	13	0
Czech Republic	5	15	12	45	38	
Ecuador	1	13	8	14	7	7
Egypt	28	6	2	5	1	
Eritrea		1	2	3		1
Ethiopia	2	4	2	1		
France	65	172	93	424	233	0
Georgia	3	4	3	18	10	
Greece	2	12	3	72	51	
Guatemala	2	2	2	0	0	0
Hungary	2	24	21	84	76	
Iran	26	121	80	550	105	
Iraq	34	70	50	53	19	
Ireland	23	93	16	75	58	
Kenya		10	3			
Korea, Rep. of	18	73	36	173	45	
Kyrgyzstan		1	4	12		
Latvia	1	4	0	16	4	0
Lesotho	0	0	0	0	0	

Country	0-4	5-13	14-18	19-44	45+	Age not known
Lithuania	2	2	3	11	4	
Malaysia	65	46	7	28	4	30
Mexico	16	99	78	225	54	104
Moldova	1	1	1	6	5	
Mongolia	4	2	2	4		1
Nepal	8	13	2	15	1	
Netherlands	1	39	23	65	67	
New Zealand	4	4	5	30	27	5
Oman	1	1	1	3	1	
Pakistan	44	57	53	59	3	
Palestine	2	4	10	12		
Panama	1	7	2	14	1	
Paraguay	2	2	3	5	2	
Peru	5	30	23	30	7	8
Philippines	2	35	28	46	12	14
Poland	10	35	33	205	99	
Portugal	2	13	4	50	31	10
Romania	1	18	6	80	90	9
Saudi Arabia	4	26	4	28	3	
Senegal	1	4	1	1		
Serbia	7	10	6	23	18	
Slovak Republic	8	9	3	34	20	
Slovenia		1	1	12	7	
South Africa	20	48	30	132	67	4
Spain	8	23	16	128	82	13
Sri Lanka	18	41	10	2	0	66
Sudan	8	42	7	19	4	12
Switzerland	1	8	9	54	43	0
Syria	2	16	9	18	3	
Turkey	45	155	94	246	80	0
United Kingdom	60	133	86	504	370	
Uruguay	1	11	8	3	2	4
Venezuela	28	50	75	150	75	
Total	813	2,453	1,573	5,983	2,858	430

Age distribution: VWD (59 countries reported age data)

Country	0-4	5-13	14-18	19-44	45+	Age not known
Argentina	1	7	20	179	95	53
Armenia		3	3	4		
Australia	27	198	125	759	639	
Azerbaijan	2	11	17	78	30	
Bangladesh	0	0	0	0	0	0
Belgium	32	221	101	570	404	10
Brazil	36	580	552	2,229	1,055	28
Bulgaria	0	4	3	35	26	
Cambodia		1				
Cameroon	1	0	0	0	0	0
Canada	49	408	349	1,700	1,057	
China	2	11	7	22	2	
Colombia	3	4	38	75	7	81
Cote d'Ivoire			1	1		
Cuba	0	7	16	51	36	0
Ecuador		14	9	37	12	7
Egypt	10	6				
Ethiopia				15	2	
France	42	196	100	466	382	0
Georgia				15	7	
Greece	10	122	67	271	214	
Guatemala	0	6	3	7	2	0
Hungary	14	150	86	623	445	
Iran	29	131	89	525	103	
Iraq	37	48	68	25	4	
Ireland	41	107	41	525	261	
Korea, Republic of	0	14	20	47	9	
Kyrgyzstan		2	2	6		
Latvia	0	0	4	65	29	3
Lesotho	0	0	0	1	0	
Lithuania	0	2	8	93	46	
Malaysia	59	120	36	164	23	62
Mexico	5	23	25	55	8	75
Moldova			1	3		
Mongolia	1	3				
Nepal		1				
Netherlands	3	30	37	59	118	
New Zealand	1	23	20	50	41	42

Country	0-4	5-13	14-18	19-44	45+	Age not known
Pakistan	26	83	87	93	19	
Palestine		4	3	3		
Panama	25	166	50	92	13	
Peru	2	20	12	50	40	20
Philippines	0	7	9	7	0	6
Poland	20	165	134	601	282	
Portugal	-	2	6	15	22	3
Romania	0	10	28	225	62	25
Saudi Arabia	4	10	34	26	1	
Senegal		1				
Serbia	2	16	8	119	44	
Slovak Republic	7	47	25	266	127	
Slovenia	2	27	10	81	34	
South Africa	6	57	59	246	184	27
Spain	4	19	24	286	263	106
Sudan	19	54	18	25	10	30
Switzerland	1	9	11	56	56	0
Syria	3	10	4	12	1	
Turkey	36	185	100	209	44	0
United Kingdom	173	880	735	4,014	3,379	6
Venezuela	51	96	155	298	141	
Total	786	4,321	3,360	15,479	9,779	584

HIV and HCV infection (People currently living with HIV or HCV)

Country	People with hemophilia	HIV+	HIV+ %	HCV+	HCV+ %	People with vWD	HIV+	HIV + %	HCV+	HCV+ %
Albania	250	1	0.4					NA		NA
Argentina	2,264	64	2.8	626	27.7	355				
Armenia	208			48	23.1	10	1	10.0	3	30.0
Austria	509	38	7.5	146	28.7			NA		NA
Azerbaijan	885					138				
Belarus	546	0	0.0	85	15.6	171		0.0	1.6	0.9
Belgium	988	50	5.1			1,338				
Brazil	10,065	113	1.1	533	5.3	4,480	8	0.2	47	1.0
Bulgaria	589	8	1.4	173	29.4	79	0	0.0	50	63.3
Cameroon	96	0	0.0	0	0.0	1	0	0.0	0	0.0
Canada	3,380	205	6.1	860	25.4	3,563	5	0.1	64	1.8
China	8,590	30	0.3	190	2.2	44				
Colombia	1,915	49	2.6	16	0.8	208	0	0.0	10	4.8
Costa Rica	194					58	12	20.7		
Cote d'Ivoire	55					2				
Croatia	477	6	1.3	198	41.5	282	0	0.0	25	8.9
Cuba	403	4	1.0	151	37.5	110	0	0.0	8	7.3
Czech Republic	833	7	0.8	110	13.2			NA		NA
Dominican Republic	249	1	0.4	3	1.2	71				
Ecuador	238	0	0.0	3	1.3	35	0	0.0	0	0.0
Egypt	5,307	0	0.0	26	0.5	455	0	0.0	0	0.0
Ethiopia	44	2	4.5	3	6.8	17				
France	5,478	452	8.3	1,681	30.7	1,186	14	1.2	146	12.3
Georgia	256	0	0.0	129	50.4	22			3	13.6
Germany	4,654	410	8.8			4,447	4	0.1		
Greece	890	66	7.4	334	37.5	684	1	0.1	30	4.4
Hungary	999	32	3.2	390	39.0	1,318	0	0.0	109	8.3
Iceland	64	0	0.0	9	14.1	96	0	0.0	0	0.0
India	13,993	162	1.2			477	0	0.0	0	0.0
Indonesia	1,388	1	0.1	57	4.1			NA		NA
Iran	5,069	200	3.9	2,500	49.3	877				
Iraq	902	0	0.0	188	20.8	182	0	0.0	32	17.6
Ireland	730	36	4.9	142	19.5	975	0	0.0	11	1.1
Israel	540	25	4.6	172	31.9	4				
Italy	3,270	220	6.7	1,156	35.4	1,650	7	0.4	69	4.2
Japan	5,346	765	14.3	2,485	46.5	944	7	0.7	132	14.0
Jordan	327	2	0.6	46	14.1	215				
Kazakhstan	1,360	18	1.3	60	4.4	460				
Korea, Rep.	1,867	19	1.0	510	27.3	90	0	0.0	1	1.1
Lebanon	165	0	0.0	15	9.1	63	0	0.0	1	1.6
Lesotho	15	0	0.0			1				
Lithuania	152			57	37.5	149				

Country	People with hemophilia	HIV+	HIV+ %	HCV+	HCV+ %	People with vWD	HIV+	HIV + %	HCV+	HCV+ %
Macedonia	315	0	0.0			90				
Malaysia	1,188	3	0.3	168	14.1	464	0	0.0	0	0.0
Mexico	4,527	24	0.5	118	2.6	191	1	0.5	2	1.0
Nepal	336	0	0.0	5	1.5	1	0	0.0	0	0.0
New Zealand	416	6	1.4	147	35.3	177	0	0.0	7	4.0
Nicaragua	217	1	0.5	75	34.6	59	1	1.7		
Oman	97	2	2.1	10	10.3	281				
Pakistan	1,436	5	0.3	329	22.9	308	0	0.0	52	16.9
Palestine	135		0.0	12	8.9	10				
Panama	262	15	5.7	21	8.0	346	0	0.0	1	0.3
Romania	1,662	1	0.1	943	56.7	350				
Saudi Arabia	326	31	9.5	88	27.0	75				
Senegal	136	0	0.0		0.0	1	0	0.0	0	0.0
Serbia	445	9	2.0	125	28.1	189	2	1.1	12	6.3
Singapore	204	0	0.0	65	31.9	58	0	0.0	2	3.4
Slovak Republic	561	0	0.0	147	26.2	506	0	0.0	23	4.5
Slovenia	203	7	3.4	89	43.8	154	0	0.0	6	3.9
South Africa	1,886	65	3.4	221	11.7	579	0	0.0	3	0.5
Spain	1,925	476	24.7	1,024	53.2	702	28	4.0	132	18.8
Sudan	650	1	0.2	23	3.5	156	0	0.0	3	1.9
Sweden	1,020	34	3.3			1,538	0	0.0	130	8.5
Syria	300	0	0.0	50	16.7	30	0	0.0	7	23.3
Thailand	1,039	10	1.0	60	5.8	69	0	0.0	1	1.4
Tunisia	250	16	6.4	140	56.0	76				
United Kingdom	6,573	329	5.0			9,187	5	0.1		
United States	17,485	2,006	11.5	6,471	37.0	13,239	26	0.2	479	3.6
Uruguay	236	1	0.4	71	30.1	316				
Uzbekistan	1,155	6	0.5	300	26.0	88			6	6.8
Venezuela	2,040	86	4.2	324	15.9	707	9	1.3	25	3.5
Viet Nam	1,815	1	0.1	114	6.3	57				
	134,390	6,073	4.5	24,242	18.0	55,261	131	0.2	1,634	3.0

Healthcare System

Number of Hemophilia Treatment Centres

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

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

Some patients seek treatment at more than one centre. Some centres treat all bleeding disorders. Not all HTCs are comprehensive care centres.

Percentage of patients on prophylaxis

Prophylaxis is regular, long term treatment with clotting factor concentrates to prevent bleeds. When a zero is entered in the table it means no patients receive prophylaxis. A blank means no data was reported.

Country	Number of HTCs	Number of HCCCs	Percent with access to HTCs or HCCCs	Percent under 18 on prophylaxis	Precise or estimate	Percent over 18 on prophylaxis	Precise or estimate
Albania	1		50	0		0	
Argentina	1	24	70				
Armenia	1		90				
Australia	2	16	100	58	estimate	29	estimate
Austria	7		100				
Azerbaijan	1	4	95	9		5	
Bahrain	1		20				
Bangladesh	3	0	60				
Belarus	7		100				
Belgium			100	80	estimate	55	estimate
Brazil	151	32	50				
Bulgaria	7		100				
Cambodia	2		60	3	estimate		
Cameroon		1	30	20	precise	40	precise
Canada		25	100				
Chile	32						
China	31	31	10	10	estimate	5	estimate
Colombia	30	9	100				
Costa Rica	1	1	100				
Cote d'Ivoire		1	55	4	precise	2	estimate
Croatia	4		100				
Cuba	16	16	100				
Cyprus	1		64				
Czech Republic	15	4	100	49	precise	11	precise
Dominican Republic	3	1	60				
Ecuador	10						
Egypt	10						
El Salvador	3		100				

Country	Number of HTC's	Number of HCCCs	Percent with access to HTC's or HCCCs	Percent under 18 on prophylaxis	Precise or estimate	Percent over 18 on prophylaxis	Precise or estimate
Eritrea	3	0	100	0		0	
Estonia	3		39				
Ethiopia	2		80				
Finland	5	1	95	100	estimate		
France					estimate		estimate
Georgia	2	1	70	0		0	
Germany	72	17	98	96	estimate	50	estimate
Greece	5		100				
Guatemala	4						
Honduras	2	2					
Hungary	19	0	100	70	estimate	30	estimate
Iceland	1		50				
India	14	40	72	30		50	
Indonesia	13	13					
Iran	29	1	70				
Iraq	5	3	90	10		0	
Ireland	4	3	100	100	precise		estimate
Israel	3	1		60	estimate		
Italy	52		100				
Jamaica	3		100				
Japan	15						
Jordan	4	0	100	30	estimate	0	precise
Kenya	1	1	40				
Korea, Republic of	16	1	85	68.3	estimate	36.9	estimate
Latvia	2	0	100				
Lebanon	1		50				
Lesotho	1		8				
Lithuania	3		100				
Macedonia	1		100	10	estimate	2	estimate
Malaysia	60	1	100	5	estimate	1	estimate
Mexico	75		76				
Moldova	2			0		0	
Mongolia	3	1	65				
Nepal	2	0	70				
Netherlands	13		100				
New Zealand	6	3	100	35	precise	13	precise
Nicaragua	1		100				
Nigeria	4	0	85	0		0	
Norway	1		100				
Oman	2	1	100	6		6	
Pakistan	14	4	10				
Palestine		0	100	0		0	
Panama	2						
Paraguay	1		43				
Peru	6	9	60				
Philippines	7	1	60				

Country	Number of HTC's	Number of HCCC's	Percent with access to HTC's or HCCC's	Percent under 18 on prophylaxis	Precise or estimate	Percent over 18 on prophylaxis	Precise or estimate
Poland	21	6	100	99	estimate	10	estimate
Portugal	19	7					
Qatar	2		50				
Romania	12	2					
Russia	5	5					
Saudi Arabia	4	1	326	40	estimate	40	estimate
Senegal	1	0		0	precise	0	precise
Serbia	7		80				
Singapore	3		80				
Slovak Republic	40	4	100	75	precise	25	estimate
Slovenia	1		100	36	precise	27	precise
South Africa	4	14			estimate		estimate
Spain	52	4					
Sri Lanka	2						
Sudan	1			0		0	
Sweden	3		100				
Switzerland	9	5	98	85	precise	33	estimate
Syria	3		40				
Thailand	42	6	100				
Tunisia	4		70				
Turkey	34		100				
Ukraine	2						
United Kingdom	81	22	100				
United States		135	70	40	estimate	16	estimate
Uruguay	21		100				
Uzbekistan	1						
Venezuela		23	100				
Viet Nam	6	1	27	0		0	
Zimbabwe	2		63				

Reported Use of Factor Concentrates: Factor VIII

Country	Factor VIII total IU	Factor VIII plasma-derived	Factor VIII recombinant	Factor VIII humanitarian aid	Factor VIII per capita	Factor VIII per capita without humanitarian aid	Total percent plasma-derived	Total percent recombinant
Albania	1,200,000	1,000,000	200,000	700,000	0.402	0.167	83%	17%
Argentina	100,800,000	75,600,000	24,600,000	600,000	2.438	2.424	75%	24%
Australia	149,723,404	17,029,250	132,694,154		6.959	6.959	11%	89%
Azerbaijan	14,545,400	12,396,400	1,530,000	300,000	1.752	1.716	85%	11%
Bangladesh	754,000	439,000	315,000	364,500	0.005	0.002	58%	42%
Belarus	19,000,000			200,000	1.969	1.948		
Belgium	57,000,000	0	57,000,000		5.468	5.468	0%	100%
Bolivia	334,079			334,079	0.034	0.000	0%	0%
Brazil	231,392,750				1.151	1.151	0%	0%
Cameroon	292,654	38,800	152,224	292,654	0.015	0.000	13%	52%
Canada	178,792,631	440,960	178,351,671	0	5.296	5.296	0%	100%
Colombia	60,955,000	34,020,000	26,685,000	250,000	1.379	1.373	56%	44%
Costa Rica	6,887,300	6,887,300		0	1.525	1.525	100%	0%
Cuba	2,209,000	2,209,000	0	72,000	0.192	0.186	100%	0%
Czech Republic	37,833,757	35,942,069	1,891,688	0	3.709	3.709	95%	5%
Dominican Rep.	1,783,000	360,000	1,423,000	210,522	0.181	0.160	20%	80%
Ecuador	8,307,800				0.562			
France	397,206,790	70,654,790	326,552,000	0	6.133	6.133	18%	82%
Georgia	3,400,000	3,350,000	50,000	96,500	0.739	0.718	99%	1%
Germany	567,752,617	289,553,834.8	278,198,782		6.900	6.900	51%	49%
Honduras	3,544,900	2,550,000	994,900	994,900	0.444	0.319	72%	28%
Hungary	72,300,000	50,000,000	22,300,000	0	7.236	7.236	69%	31%
India	5,350,000	4,500,000	850,000	1,593,700	0.005	0.003	84%	16%
Indonesia	8,006,750	6,240,000	1,766,750	628,880	0.033	0.030	78%	22%
Iran	120,000,000	120,000,000			1.560	1.560	100%	0%
Iraq	20,000,000	0	20,000,000	0	0.674	0.674	0%	100%
Ireland	32,896,529	0	32,896,529	0	7.116	7.116	0%	100%
Japan	369,540,000	91,690,000	277,850,000		2.914	2.914	25%	75%
Jordan	5,702,306			308,350	0.890	0.842	0%	0%
Kenya	331,908	38,800	293,108	331,908	0.008	0.000	12%	88%
Korea, Rep. of	138,758,500	73,298,000	65,460,500		2.853	2.853	53%	47%
Latvia	2,884,190	2,884,190	0	0	1.300	1.300	100%	0%
Lebanon	2,000,000			357,136	0.485	0.398		
Macedonia	3,564,600	3,564,600	57,500		1.720	1.720	100%	2%
Malaysia	14,810,000	14,620,000	155,750	0	0.524	0.524	99%	1%
Mexico	67,140,750	64,494,500	2,646,250	2,408,650	0.597	0.576	96%	4%
Moldova	1,742,400	376,100	1,339,000	1,369,900	0.404	0.086	22%	77%
Mongolia	249,200	50,000	199,200	249,200	0.081	0.000	20%	80%
New Zealand	41,383,600			0	9.732	9.732	0%	0%
Nigeria	313,604	0	313,604	313,604	0.002	0.000	0%	100%

Country	Factor VIII total IU	Factor VIII plasma-derived	Factor VIII recombinant	Factor VIII humanitarian aid	Factor VIII per capita	Factor VIII per capita without humanitarian aid	Total percent plasma-derived	Total percent recombinant
Oman	1,201,000	11,250	1,200,000	0	0.405	0.405	1%	100%
Pakistan	766,951	258,079	508,872	666,951	0.004	0.001	34%	66%
Palestine	1,800,000	1,800,000		155,000	0.716	0.654	100%	0%
Peru	16,352,500	13,892,500	2,460,000	60,000	0.547	0.545	85%	15%
Philippines	2,759,300	510,363	2,248,937	2,248,937	0.028	0.005	18%	82%
Poland	181,548,612	179,495,000.00	26,500	0	4.720	4.720	99%	0%
Portugal	42,027,750	16,404,500	25,623,250		3.915	3.915	39%	61%
Romania	11,220,768			269,655	0.511	0.499	0%	0%
Russia	592,000,000	522,549,500	69,704,500	0	4.247	4.247	88%	12%
Saudi Arabia	40,096,000	30,000,000.00	10,096,000		1.558	1.558	75%	25%
Serbia	10,045,050	10,045,050			1.368	1.368	100%	0%
Slovak Republic	27,700,000			0	5.064	5.064	0%	0%
Slovenia	11,949,539	3,260,539	8,160,500		5.965	5.965	27%	68%
South Africa	40,848,000	40,600,000	248,000	0	0.832	0.832	99%	1%
Sri Lanka	4,710,502			373,976	0.219	0.202	0%	0%
Sudan	2,179,125	1,844,125	335,000	335,000	0.050	0.042	85%	15%
Switzerland	31,500,000	7,900,000	23,600,000	0	4.132	4.132	25%	75%
Syria	7,000,000			216,750	0.315	0.306		
Thailand	5,150,000			424,982	0.077	0.070	0%	0%
Tunisia	4,250,000			153,640	0.401	0.387		
Turkey	114,056,500	87,894,500	26,162,000		1.466	1.466	77%	23%
U.K.	468,320,897	62211280	406109617	0	7.511	7.511	13%	87%
United States	1,600,000,000	500,000,000	1,100,000,000		5.157	5.157	31%	69%
Uzbekistan	533,770	50,000	483,770	533,770	0.019	0.000	9%	91%
Venezuela	41,000,000	17,000,000	24,000,000	0	1.506	1.506	41%	59%
Viet Nam	4,132,000	4,132,000		354,280	0.046	0.042	100%	0%
	6,013,837,683	2,484,086,280	3,157,733,556	17,769,424	1.433	1.418	42%	53%

The quantities of factor VIII in the chart above are as reported to the WFH and are not independently verified. In some cases the numbers reported may be for one region or hospital only. Some countries report the amount of factor concentrate *consumed* in the year 2010 while others report the amount *purchased*. Where available the percentage of plasma-derived and recombinant product used is reported this distribution includes humanitarian aid. In cases where the amount of humanitarian aid reported is lower than the WFH records for 2010, the higher WFH number was used. 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.

Reported Use of Factor Concentrates: Factor IX

Country	Factor IX total IU	Factor IX plasma-derived	Factor IX recombinant	Factor IX humanitarian aid	Factor IX per capita	Factor IX per capita without humanitarian aid	Total percent plasma-derived	Total percent recombinant
Albania	300,000				0.10044	0.10044	0%	0%
Argentina	14,800,000	11,900,000	2,900,000		0.35798	0.35798	80%	20%
Australia	25,705,750	2,126,500	23,579,250		1.19474	1.19474	8%	92%
Azerbaijan	1,104,000	1,104,000			0.13296	0.13296	100%	0%
Bangladesh	50,000	50,000	0	50,000	0.00032	0.00000	100%	0%
Bolivia	50,000			50,000	0.00503	0.00000	0%	0%
Brazil	48,723,350	48,723,350			0.24228	0.24228	100%	0%
Cameroon	12,593	10,563	2,030	2,030	0.00065	0.00055	84%	16%
Canada	43,612,325	6,640,082	36,972,243	0	1.29184	1.29184	15%	85%
Colombia	11,969,000	8,364,000	3,600,000	5,000	0.27076	0.27065	70%	30%
Costa Rica	3,834,000	3,834,000		0	0.84894	0.84894	100%	0%
Cuba	96,000	84,000	12,000	12,000	0.00836	0.00732	88%	13%
France	62,665,710	27,523,210	35,142,500	0	0.96754	0.96754	44%	56%
Georgia	600,000	600,000			0.13041	0.13041	100%	0%
Germany	83,105,817.9				1.01000	1.01000	0%	0%
Honduras	118,700	75,000	43,700	43,700	0.01486	0.00939	63%	37%
Hungary	2,700,000	2,700,000	0	0	0.27021	0.27021	100%	0%
India	1,100,000	1,100,000	0	1,000,000	0.00094	0.00009	100%	0%
Iran	15,000,000				0.19500	0.19500	0%	0%
Iraq	5,000,000	0	5,000,000	0	0.16851	0.16851	0%	100%
Ireland	9,457,250	0	9,457,250	0	2.04573	2.04573	0%	100%
Jordan	70,000			70,000	0.01093	0.00000	0%	0%
Korea, Rep. of	26,194,500	2,928,000	23,266,500		0.53858	0.53858	11%	89%
Latvia	485,000	485,000	0	0	0.21867	0.21867	100%	0%
Macedonia	953,500	953,500	0		0.46016	0.46016	100%	0%
Malaysia	8,590,000	8,590,000	0	0	0.30380	0.30380	100%	0%
Mexico	11,372,000	11,372,000			0.10111	0.10111	100%	0%
Moldova	74,500	74,500		74,500	0.01726	0.00000	100%	0%
Mongolia	43,500	43,500		43,500	0.01409	0.00000	100%	0%
New Zealand	10,345,900			0	2.43303	2.43303	0%	0%
Nigeria	0	0	0	0	0.00000	0.00000	NA	NA
Oman	0			0	0.00000	0.00000	NA	NA
Pakistan	187,151	187,151		187,151	0.00101	0.00000	100%	0%
Palestine	120,000	120,000			0.04772	0.04772	100%	0%
Peru	4,341,000	4,341,000	0	0	0.14515	0.14515	100%	0%
Philippines	294,312	25,875	268,437	294,312	0.00295	0.00000	9%	91%
Poland	20,116,000	20,109,000	7,000	0	0.52299	0.52299	100%	0%
Portugal	6,719,000	4,150,000	2,569,000		0.62585	0.62585	62%	38%
Russia	70,010,450	70,010,450	0	0	0.50226	0.50226	100%	0%
Saudi Arabia	1,681,500	1,681,500	0		0.06535	0.06535	100%	0%
Serbia	894,700	894,700			0.12181	0.12181	100%	0%

Country	Factor IX total IU	Factor IX plasma-derived	Factor IX recombinant	Factor IX humanitarian aid	Factor IX per capita	Factor IX per capita without humanitarian aid	Total percent plasma-derived	Total percent recombinant
Slovak Republic	2,800,000		0	0	0.51185	0.51185	0%	0%
Slovenia	528,500				0.26384	0.26384	0%	0%
South Africa	4,800,000	4,800,000	0	0	0.09774	0.09774	100%	0%
Sri Lanka	800,000				0.03719	0.03719	0%	0%
Sudan	243,000	243,000		0	0.00553	0.00553	100%	0%
Switzerland	5,500,000	5,000,000	500,000	0	0.72146	0.72146	91%	9%
Turkey	21,427,200				0.27540	0.27540	0%	0%
U.K.	82,250,651	9695050	72555601	0	1.31921	1.31921	12%	88%
United States	250,100,000	100,000	250,000,000		0.80617	0.80617	0%	100%
Venezuela	7,000,000	7,000,000		0	0.25713	0.25713	100%	0%
Viet Nam	0	0	0	0	0.00000	0.00000	NA	NA
	867,946,860	267,638,931	465,875,511	1,832,193	0.24038	0.23988	31%	54%

The quantities of factor IX in the chart above are as reported to the WFH and are not independently verified. In some cases the numbers reported may be for one region or hospital only. Some countries report the amount of factor concentrate consumed in the year 2010 while others report the amount purchased. Where available the percentage of plasma-derived and recombinant product used is reported, including humanitarian aid. In cases where the amount of humanitarian aid reported is lower than the WFH records for 2010, the higher WFH number was used. 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.

Sample Survey Questionnaire

A. National hemophilia organization

Organization name	
Address	
City	
State, Province, Region, Prefecture, County	
Postal/ZIP Code	
Country	
Phone	
Fax	
E-mail	
Website	

B. Identified patients

(Please DO NOT estimate or guess)	Number	Not known
1. Number of identified people with hemophilia A and B (PWH)		<input type="checkbox"/>
2. Number of identified people with von Willebrand disease (vWD)		<input type="checkbox"/>
3. Number of identified people with other hereditary bleeding disorders (including rare factor deficiencies and inherited platelet disorders)		<input type="checkbox"/>

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

4. What is the source of the numbers provided for this survey?	Check one <input type="checkbox"/> A registry of all PWH and other inherited bleeding disorders in your country. <input type="checkbox"/> A registry of all PWH and other inherited bleeding disorders in your country's hemophilia treatment centres. <input type="checkbox"/> Count information provided by all of your country's hemophilia treatment centres <input type="checkbox"/> Count information provided by some of your country's hemophilia treatment centres. <input type="checkbox"/> Other (Describe):
Is your database updated throughout the year or only once per year?	<input type="checkbox"/> Ongoing update (can be updated anytime) <input type="checkbox"/> Yearly update (the registry is updated once each year) <input type="checkbox"/> Other (please describe):
Who updates the database?	<input type="checkbox"/> Doctors update the database <input type="checkbox"/> Patient organization updates the database <input type="checkbox"/> Hospitals or clinics update the database <input type="checkbox"/> Other (please describe):

5. Number of people with hemophilia and von Willebrand disease by age group

Age group	Number with hemophilia A	Number with hemophilia B	Number with VWD
0-4 years old			
5 - 13 years old			
14 - 18 years old			
19 - 44 years old			
45 years or older			
Patients with age unknown			
No age data	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6.Type of hereditary bleeding disorder

Diagnosis	Total	Male	Female	Gender unknown	No data
Hemophilia A					<input type="checkbox"/>
Hemophilia B					<input type="checkbox"/>
Hemophilia, type unknown					<input type="checkbox"/>
von Willebrand disease					<input type="checkbox"/>
Factor I deficiency					<input type="checkbox"/>
Factor II deficiency					<input type="checkbox"/>
Factor V deficiency					<input type="checkbox"/>
Factor V+VIII deficiency					<input type="checkbox"/>
Factor VII deficiency					<input type="checkbox"/>
Factor X deficiency					<input type="checkbox"/>
Factor XI deficiency					<input type="checkbox"/>
Factor XIII deficiency					<input type="checkbox"/>
Other hereditary bleeding disorders: type unknown					<input type="checkbox"/>
Platelet disorders: Glanzmann's thrombasthenia					<input type="checkbox"/>
Platelet disorders: Bernard Soulier Syndrome					<input type="checkbox"/>
Platelet disorders: other or unknown					<input type="checkbox"/>

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

Factor level below 5% <input type="checkbox"/>	Severe bleeding symptoms <input type="checkbox"/>	Other <input type="checkbox"/> (please describe):	No data <input type="checkbox"/>
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How are patients with von Willebrand disease identified?

Laboratory diagnosis <input type="checkbox"/>	Severe bleeding symptoms <input type="checkbox"/>	Other <input type="checkbox"/> (please describe):	No data <input type="checkbox"/>
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8. Number of identified people with hemophilia by diagnosis of severity

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					<input type="checkbox"/>
Hemophilia A female					<input type="checkbox"/>
Hemophilia B male					<input type="checkbox"/>
Hemophilia B female					<input type="checkbox"/>

9. Number of severe VWD patients

Total number of severe (type 3) VWD patients	Number of VWD patients receiving replacement therapy	Number of VWD patients with severe bleeding symptoms	No Data
			<input type="checkbox"/>

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

Type of hemophilia	Number with current inhibitors	No Data
Hemophilia A		<input type="checkbox"/>
Hemophilia B		<input type="checkbox"/>

11. Products used to treat hemophilia: What percentage of patients is treated with the following products?

Plasma	%
Cryoprecipitate	%
Plasma-derived concentrate	%
Recombinant concentrate	%
DDAVP (Desmopressin)	%

12. Products used to treat VWD: What percentage of patients is treated with the following products?

Plasma	%
Cryoprecipitate	%
Plasma-derived concentrate	%
DDAVP (Desmopressin)	%



13. HIV and hepatitis C infection among living people with hemophilia

Infectious Disease	Number of people infected	Percentage of people tested	No Data
HIV			<input type="checkbox"/>
Hepatitis C			<input type="checkbox"/>

14. HIV and hepatitis C infection among living people with von Willebrand disease

Infectious Disease	Number of people infected	Percentage of people tested	No Data
HIV			<input type="checkbox"/>
Hepatitis C			<input type="checkbox"/>

15. Number and cause of deaths of people with bleeding disorders (January 1-December 31, 2010)

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

C. Hemophilia care system in your country

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

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

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

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

17. What percentage of children (under age 18) are on prophylaxis?		Precise: <input type="checkbox"/> Estimate: <input type="checkbox"/>	Not known <input type="checkbox"/>
What percentage of adults (over age 18) are on prophylaxis?		Precise: <input type="checkbox"/> Estimate: <input type="checkbox"/>	Not known <input type="checkbox"/>

D. The cost and use of factor concentrates

18. Annual usage of factor concentrates	Factor VIII	Factor IX	Not known
How many international units (IU) of factor concentrates were used in your country in 2010?			<input type="checkbox"/>
How many international units of plasma-derived concentrates were used in your country in 2010?			<input type="checkbox"/>
How many international units of recombinant concentrates were used in your country in 2010?			<input type="checkbox"/>
How many international units were humanitarian aid ?			<input type="checkbox"/>

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 <input type="checkbox"/> Yes <input type="checkbox"/>	Tax rate:
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18. Factor VIII concentrates used in 2010

(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
<input type="checkbox"/>	Aafact	Sanquin	
<input type="checkbox"/>	Advate rAHF PFM	Baxter Bioscience	
<input type="checkbox"/>	Alphanate	Grifols	
<input type="checkbox"/>	Amofil	Sanquin OY	
<input type="checkbox"/>	Beriate P	CSL Behring	
<input type="checkbox"/>	BIOSTATE	CSL Bioplasma	
<input type="checkbox"/>	Conco-eight-HT	Benesis	
<input type="checkbox"/>	Confact F	Kaketsuken	
<input type="checkbox"/>	Cross Eight M	Japanese Red Cross	
<input type="checkbox"/>	Emoclot D.I.	Kedrion	
<input type="checkbox"/>	FACTANE	LFB	
<input type="checkbox"/>	Factor 8 Y	BioProducts Lab.	
<input type="checkbox"/>	Faktor VIII SDH Intersero	Intersero	
<input type="checkbox"/>	Fanhdi	Grifols	
<input type="checkbox"/>	GreenEight	GreenCross	
<input type="checkbox"/>	GreenGene	GreenCross	

<input type="checkbox"/>	GreenMono	Greencross Corp	
<input type="checkbox"/>	Haemate P (= Haemate HS)	CSL Behring	
<input type="checkbox"/>	Haemoctin SDH	Biotest	
<input type="checkbox"/>	Haemosolvate Factor VIII	National Bioproducts	
<input type="checkbox"/>	Helixate NexGen = Helixate FS	CSL Behring	
<input type="checkbox"/>	Hemofil M AHF	Baxter BioScience	
<input type="checkbox"/>	HEMORAAS SD plus H	Shanghai RAAS	
<input type="checkbox"/>	HEMORAAS-HP, SD plus H	Shanghai RAAS	
<input type="checkbox"/>	HEMORAAS-IP, SD plus H	Shanghai RAAS	
<input type="checkbox"/>	Humate P	CSL Behring	
<input type="checkbox"/>	Immunate	Baxter BioScience	
<input type="checkbox"/>	Koate DVI	Talecris	
<input type="checkbox"/>	Kogenate FS = KOGENATE Bayer (in EU)	Bayer	
<input type="checkbox"/>	Monoclate P	CSL Behring	
<input type="checkbox"/>	Octanate	Octapharma	
<input type="checkbox"/>	Octanativ-M	Octapharma	
<input type="checkbox"/>	Optivate	Bio Products Laboratory	
<input type="checkbox"/>	Recombinate rAHF	Baxter BioScience	
<input type="checkbox"/>	ReFacto AF	Pfizer (Wyeth)	
<input type="checkbox"/>	Replenate	Bio Products Laboratory	
<input type="checkbox"/>	Wilate	Octapharma	
<input type="checkbox"/>	Xyntha	Pfizer (Wyeth)	
<input type="checkbox"/>	Other:		

19. Factor IX concentrates

(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
<input type="checkbox"/>	Aimafix	Kedrion	
<input type="checkbox"/>	AlphaNine SD	Grifols	
<input type="checkbox"/>	BeneFIX	Wyeth	
<input type="checkbox"/>	Berinin-P = Berinin HS	CSL Behring	
<input type="checkbox"/>	BETAFACT	LFB	
<input type="checkbox"/>	Christmassin-M	Benesis	
<input type="checkbox"/>	Factor IX Grifols	Grifols	
<input type="checkbox"/>	Faktor IX SDN	Biotest	
<input type="checkbox"/>	Hemo-B-RAAS	Shanghai RAAS	
<input type="checkbox"/>	Immunine	Baxter BioScience	
<input type="checkbox"/>	MonoFIX-VF	CSL Bioplasma	
<input type="checkbox"/>	Mononine	CSL Behring	

<input type="checkbox"/>	Nanotiv	Octapharma	
<input type="checkbox"/>	Nonafact	Sanquin	
<input type="checkbox"/>	Novact M	Kaketsuken	
<input type="checkbox"/>	Octanine F	Octapharma	
<input type="checkbox"/>	Replenine - VF	BioProducts Lab.	
<input type="checkbox"/>	Other:		

20. Prothrombin complex concentrates

(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
<input type="checkbox"/>	Bebulin VH	Baxter BioScience	
<input type="checkbox"/>	Beriplex P/N	CSL Behring	
<input type="checkbox"/>	Cofact	Sanquin	
<input type="checkbox"/>	Facnyne	Greencross Corp	
<input type="checkbox"/>	Haemosolvex Factor IX	National Bioproducts	
<input type="checkbox"/>	HT DEFIX	SNBTS	
<input type="checkbox"/>	KASKADIL	LFB	
<input type="checkbox"/>	Octaplex	Octapharma	
<input type="checkbox"/>	PPSB-human SD/Nano 300/600	German Red Cross NSTOB	
<input type="checkbox"/>	Profilnine SD	Grifols	
<input type="checkbox"/>	Proplex - T	Baxter BioScience	
<input type="checkbox"/>	Prothrombinex- VF	CSL Bioplasma	
<input type="checkbox"/>	Prothromplex-T	Baxter BioScience	
<input type="checkbox"/>	Prothroras	Shanghai RAAS	
<input type="checkbox"/>	UMAN Complex D.I.	Kedrion	
<input type="checkbox"/>	Other:		

21. Other products

(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
<input type="checkbox"/>	Clottagen (fibrinogen)	LFB	
<input type="checkbox"/>	Fibrinogen HT	Benesis	
<input type="checkbox"/>	FIBRORAAS (fibrinogen)	Shanghai RAAS	
<input type="checkbox"/>	Haemocomplettan P = Haemocomplettan HS (fibrinogen)	CSL Behring	
<input type="checkbox"/>	Riastap	CSL Behring	
<input type="checkbox"/>	Factor VII	Baxter BioScience	
<input type="checkbox"/>	Factor VII	Bio Products	
<input type="checkbox"/>	FACTEUR VII	LFB	
<input type="checkbox"/>	Factor X P Behring	CSL Behring	

<input type="checkbox"/>	Factor XI	Bio Products	
<input type="checkbox"/>	HEMOLEVEN (Factor XI)	LFB	
<input type="checkbox"/>	WILFACTIN (Von Willebrand Factor)	LFB	
<input type="checkbox"/>	Fibrogammin P (=Fibrogammin HS) (Factor XIII)	CSL Behring	
<input type="checkbox"/>	FEIBA	Baxter	
<input type="checkbox"/>	NovoSeven (=Niasase) (activated factor VII)	NovoNordisk	Price: Vial size:
<input type="checkbox"/>	Coagil 7 (activated factor VII)	Pharmstandard	Price: Vial size:
<input type="checkbox"/>	Other:		



Glossary of terms

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

PWH: Person with hemophilia

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

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

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

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





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