

Hæmophilia Care in Europe | Heat Map: Results of the survey of 37 countries

This heat map is designed to guide your eye to the items that are either positive or negative. You can identify where countries perform well or meet standards by locating the color **blue**. You can also look for **orange** in sectors where countries would need to improve their performance. The color **yellow** represents a performance in between.



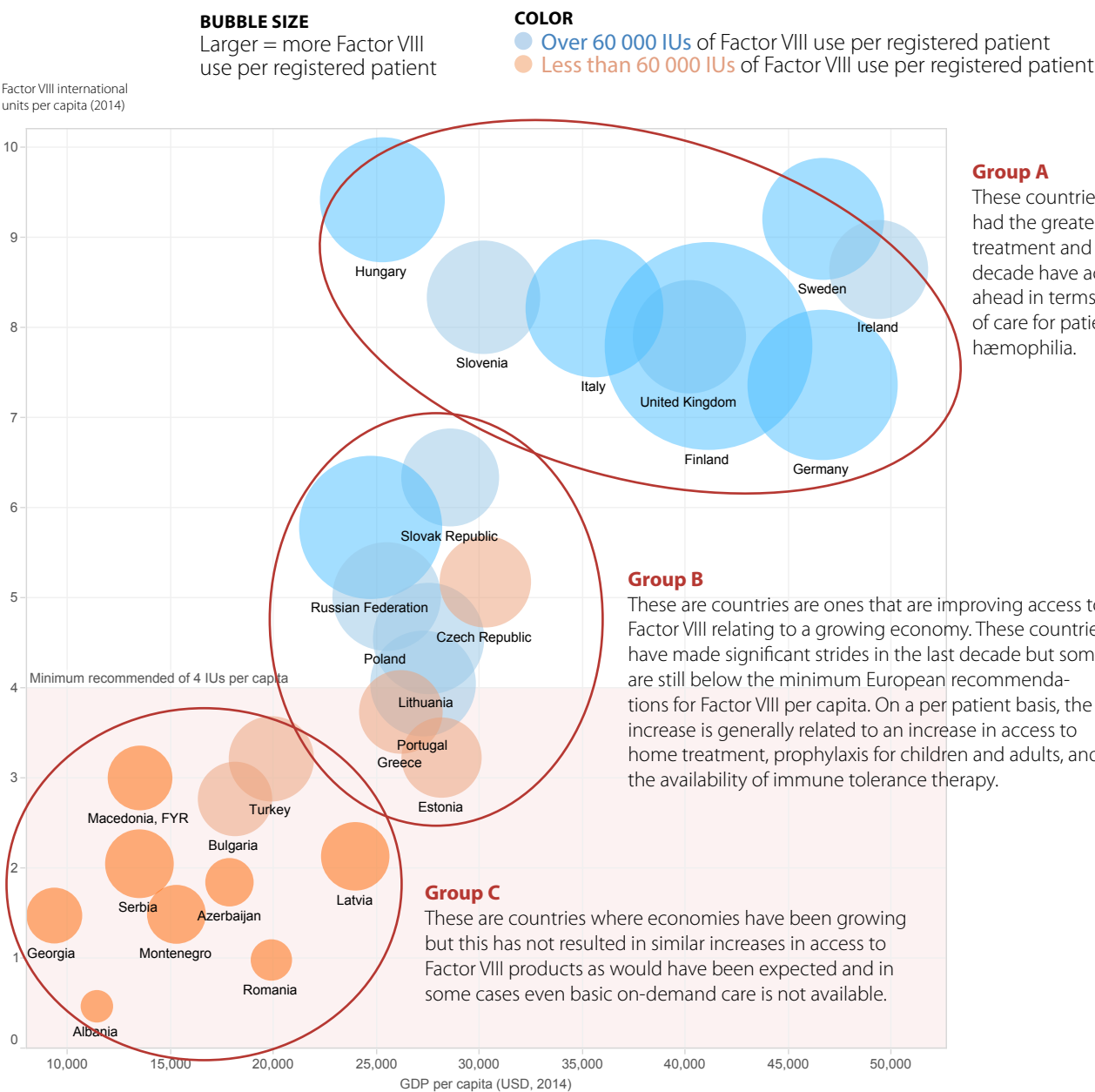
Country		Hungary	Sweden	Ireland	Slovenia	Italy	United Kingdom	Finland	Germany	Belgium	Slovak Republic	Switzerland	Russia	Norway	Czech Republic	Poland	Lithuania	Spain	Portugal	Greece	Estonia	Turkey	Macedonia	Bulgaria	Latvia	Serbia	Azerbaijan	Montenegro	Georgia	Romania	Ukraine	Albania	Kyrgyz Republic	Armenia	Austria	Denmark	Israel	Netherlands	
International units per capita	Factor VIII	9.4	9.2	8.64	8.33	8.2	7.89	7.79	7.35	6.7	6.33	5.83	5.78	5.42	5.17	5.01	4.55	4.53	4.04	3.72	3.22	3.21	3	2.76	2.12	2.04	1.84	1.48	1.46	0.97	0.5	0.46	0.1	No response on Factor VIII >>					
	Factor IX	0.606	NR	2.468	0.462	1.099	1.33	1.426	0.849	NR	0.41	0.949	0.682	NR	NR	0.676	0.862	0.78	0.538	0.485	0.232	0.508	0.8	0.189	0.311	0.24	0.204	0.158	0.162	0.104	0.09	0.231	0.01	NR	NR	NR	NR	NR	
	<< Above Factor VIII recommendation																				>> Below Factor VIII recommendation <<																		
Organisation of care	Comprehensive Care Centres (CCC's)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	No	Yes	No	Yes	Yes	No	Yes	Yes	No	Yes	No	No	No	No	No	Yes	Yes	
	Haemophilia Treatment Centres	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	No	No	No	No		
	National Haemophilia Council or Co-ordinating Group	No	No	Yes	Yes	No	Yes	No	No	Yes	Yes	No	No	No	Yes	Yes	No	No	No	No	No	No	Yes	Yes	No	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes		
	Number of groups in decision-making on haemophilia care	2	3	3	3	1	3	2	3	3	3	1	3	2	2	3	1	2	3	2	2	2	3	2	2	3	2	2	2	3	2	2	2	2	2	2	3		
	Number of groups choosing haemophilia treatment products	2	3	3	2	2	3	3	2	1	3	1	3	2	2	2	2	1	2	3	2	1	2	2	1	3	2	1	3	1	3	2	2	2	3	1	1		
	National Tender for procurement of factor concentrates	Yes	No	Yes	Yes	No	Yes	No	No	No	No	Yes	No	Yes	No	Yes	Yes	Yes	No	Yes	No	Yes	NR	Yes	Yes	No	Yes	Yes	Yes	NR	No	Yes	No	No	NR	No	No	No	
Treatment regimens	Home Treatment	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	No	No	No	No	No	No	Yes	Yes	
	% of people with haemophilia using home treatment	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	51-75%	76-100%	51-75%	76-100%	10-50%	<10%	N/A	76-100%	10-50%	N/A	N/A	N/A	N/A	N/A	No	Yes		
	Treatment delivered to the patient's home	No	Some	Yes	No	Some	Yes	Some	No	No	Some	Yes	Some	Some	No	Some	No	No	No	No	Yes	Some	Yes	No	No	No	No	Some	No	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Yes	Yes	
	Prophylaxis treatment availability	Some	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Some	Yes	Some	Yes	Yes	Children	Some	Yes	Yes	Children	Children	Children	Some	Some	Children	No	Children	Some	No	No	No	No	No	Yes	Yes		
	Children currently on prophy (%)	76-100%	76-100%	76-100%	76-100%	NR	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	0	51-75%	26-50%	0	0	0	0	0	0	
	Adults currently on prophy (%)	26-50%	76-100%	76-100%	76-100%	NR	51-75%	51-75%	51-75%	76-100%	26-50%	26-50%	26-50%	76-100%	26-50%	51-75%	1-25%	26-50%	26-50%	26-50%	26-50%	100%	51-75%	1-25%	100%	1-25%	1-25%	1-25%	1-25%	0	0	0	0	0	0	0	0	0	0
Access to specialist services	Access to ITI (% of people with inhibitors)	76-99%	100%	100%	100%	NR	100%	100%	100%	100%	100%	100%	51-75%	100%	100%	76-99%	1-25%	100%	51-75%	100%	1-25%	1-25%	1-25%	1-25%	1-25%	1-25%	1-25%	0	1-25%	0	0	0	0	0	0	0	0	0	
Access to specialist services	Emergency medicine and acute surgery	Yes	Yes	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	
	Paediatrics	Yes	Yes	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
	Infectious disease specialists (especially HIV)	Yes	Sometimes	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	NR	Yes	Yes	Sometimes	Yes	Sometimes	Yes	Never	Yes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	
	Hepatology	Sometimes	Yes	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Sometimes	Yes	Yes	Yes	Sometimes	NR	Yes	Sometimes	Sometimes	Yes	Sometimes	Sometimes	Yes	Sometimes	Yes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes
	Rheumatology	Sometimes	Yes	Yes	Yes	Never	Sometimes	Yes	Yes	Yes	Yes	Sometimes	Yes	Never	Yes	Yes	Yes	Sometimes	Sometimes	Sometimes	Yes	Sometimes	NR	Never	Never	Sometimes	Yes	Sometimes	Never	Yes	NR	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	
	Orthopaedics	Sometimes	Yes	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Sometimes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
	Physiotherapy	Sometimes	Yes	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Sometimes	Yes	Sometimes	Sometimes	Yes	Sometimes	Yes	Yes	Sometimes	Sometimes	Yes	Yes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	
	Dentistry	Never	Yes	Yes	Yes	Sometimes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Sometimes	Sometimes	Yes	Never	Yes	Yes	Sometimes	Sometimes	Yes	Yes	Sometimes	Sometimes	Yes	Never	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	
	Obstetrics and Gynaecology	Sometimes	Yes	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Sometimes	Yes	Sometimes	Yes	Sometimes	Sometimes	Sometimes	Yes	Yes	Yes	Sometimes	Sometimes	NR	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	
	Genetics	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Sometimes	Yes	Yes	Yes	Sometimes	Yes	Yes	Sometimes	Yes	Yes	Sometimes	Yes	Sometimes	Yes	Sometimes	Sometimes	Sometimes	Sometimes	Never	Sometimes	Never	Sometimes	Never	Never	Never	Never	Never	Never	Never	
	Social and psychological support	Never	Yes	Yes	Yes	Sometimes	Sometimes	Yes	Sometimes	Yes	Yes	Yes	Yes	Never	Yes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Never	Sometimes	Sometimes	Never	Never	Sometimes	Sometimes	Never	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes
	Pain management	Never	Yes	Yes	Yes	Never	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Never	Yes	Sometimes	Yes	Sometimes	Sometimes	Sometimes	Sometimes	Never	Sometimes	Sometimes	Never	Never	Sometimes	Sometimes	Never	Yes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes
	General surgery	Sometimes	Yes	Yes	Yes	Never	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Sometimes	Sometimes	Sometimes	Yes	Yes	Sometimes	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes
Urology	Sometimes	Yes	Yes	Yes	Never	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Sometimes	Yes	Yes	Yes	Sometimes	Sometimes	Sometimes	Yes	Yes	Sometimes	Never	Sometimes	Never	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	
Share of Expected Bleeding Disorder Prevalence	Haemophilia A	87%	87%	122%	93%	62%	87%	26%	46%	75%	94%	NR	40%	66%	88%	61%	54%	56%	52%	77%	71%	61%	102%	72%	66%	62%	110%	67%	82%	41%	63%	36%	79%	72%	68%	61%	75%		
	Haemophilia B	74%	70%	158%	37%	42%	61%	18%	27%	57%	44%	NR	23%	62%	42%	35%	25%	27%	35%	53%	25%	36%	170%	32%	44%	36%	44%	26%	40%	35%	24%	69%	15%	23%	45%	54%	36%	62%	
	von Willebrand Disease	14%	15%	25%	9%	4%	16%	9%	4%	16%	11%	NR	1%	16%	8%	4%	11%	2%	0%	10%	7%	1%	10%	1%	6%	4%	2%	0%	1%	0%	1%	0%	0%	1%	1%	7%	0%	6%	
Haemophilia replacement therapy	Pasma-derived factor concentrate	Rarely	Rarely	Rarely	Rarely	Always	Rarely	Always	Always	Always	Always	Always	Always	Rarely	Always	Always	Always	Rarely	Always	Rarely	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Rarely	Always	Always	Always	Always	Always	
	Recombinant factor concentrate	Rarely	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	
	Plasma	Never	Rarely	Never	NR	Never	Rarely	Never	Rarely	Never	Never	Rarely	Never	Never	Never	NR	Never	Never	NR	Never	Never	Rarely	Never	Never	Never	Rarely	Rarely	Never	NR	Rarely	Always	Rarely	Always	Always	Always	Always	Always		
	Cryoprecipitate	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	NR	Rarely	Never	Never	NR	Never	Never	NR	Never	Never	Never	Never	Never	Never	Rarely	Rarely	Never	Rarely	Rarely	Always	Rarely	Always	Always	Always	Always	Always		
VWD replacement therapy	Plasma-derived factor concentrate	Rarely	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Rarely	Always	Always	Always	Always	Never	Always	Never	Always	Always	Rarely	NR	Always	Always	Rarely	Rarely	Always	Always	Always	Always		
	DDAVP	Rarely	Always	Always	Always	Always	Always	Always	Always	Always	Rarely	Always	Never	Always	Never	Always	Rarely	Always	Always	Always	Always	Always	Never	Always	Always	Rarely	Rarely	Always	NR	Rarely	Always	NR	Rarely	Always	Always	Always	Always		
	Plasma	NR	Rarely	Never	Never	NR	Rarely	Never	Rarely	Never	Never	Rarely	Rarely	Never	Never	NR	NR	Never	NR	Never	Never	Always	Rarely	Never	Never	Rarely	Rarely	Never	Always	Rarely	Always	NR	Always	Always	Always	Always	Always		
	Cryoprecipitate	NR	Never	Never	Never	NR	Rarely	Never	Never	Never	Never	NR	Rarely	Never	Never	NR	NR	Never	NR	Never	Never	Always	Never	Never	Never	Rarely	Rarely	NR	Rarely	Rarely	NR	Always	Always	Always	Always	Always	Always		

Populations has been taken from World Bank data. The estimated prevalence for Hæmophilia A is 1:10,000, for Hæmophilia B 1:33,000 and for vWD 1:1,000.

Significant disparity of access across Europe

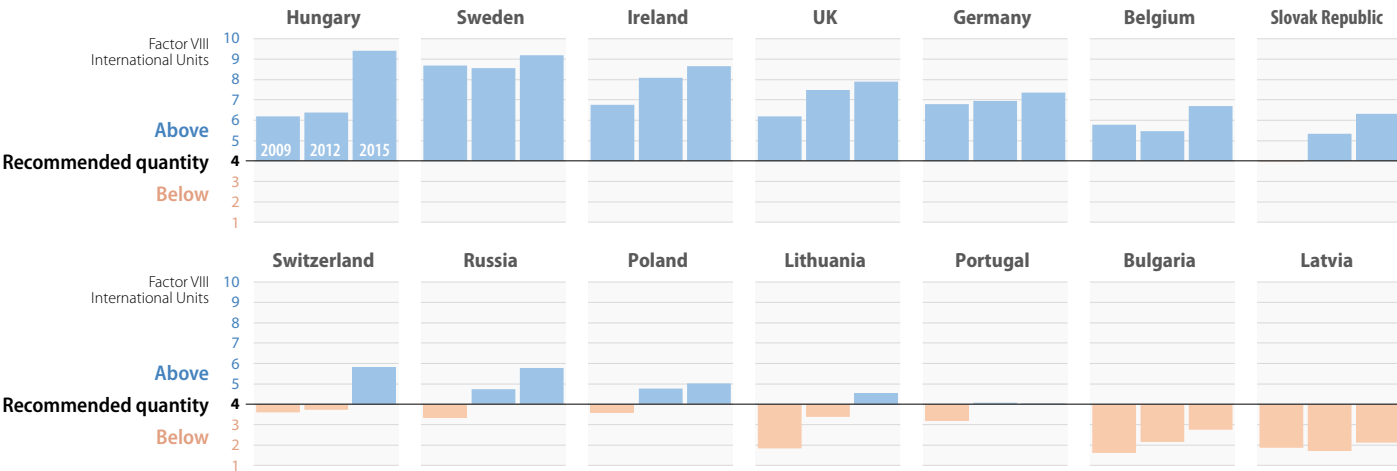
The graph below summarizes the use of Factor VIII per capita compared to GDP per capita for each country that provided data for 2015. The graph highlights the significant difference in the amount of Factor VIII available in a country and compares this to GDP, which is used as indication of ability to pay. The size of the circles for each country represent the Factor VIII use based on reported registered patients. This is used to identify the access by those patients with haemophilia within each country to treatment and begin to understand the impact of a registry.

Overall, there is a clear disparity across Europe with three distinct groups developing. In the coming years there should be an emphasis on growing the Factor VIII per capita, Factor VIII per patient and the optimisation of Factor VIII use through registries to ensure equity across Europe for all patients. The disparity already present in the three groups should not increase.



A positive trend in meeting EDQM Factor VIII recommendation

For countries that have reported in all three surveys, there is a positive trend in terms of access to Factor VIII products represented by Factor VIII per capita. Whilst all countries have increased the overall volumes, there are still some countries that remain below the minimum recommended European standards after six years of improvement.



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HÆMOPHILIA CARE IN EUROPE

Survey of 37 countries



Europe is a disparate continent with a wide range of economic conditions and health systems in individual countries. In 2008, the *European principles of haemophilia care* were drafted by an interdisciplinary group of haemophilia physicians with input from key patient opinion leaders and endorsed by EHC and EAHAD.

These principles are:

1. Establishment of a central haemophilia organisation in each country with supporting local group
2. National haemophilia patient registries
3. A network of multidisciplinary comprehensive care centres and complementary haemophilia treatment centres
4. Partnership of health care professionals and patients in the delivery of haemophilia care
5. Safe and effective concentrates at optimum treatment levels
6. Home treatment and delivery
7. Prophylaxis
8. Specialist services and emergency care
9. Management of inhibitors
10. Encouragement of education and research

In 2009, the EHC carried out a survey in order to determine the extent to which haemophilia care in across the continent of Europe compared with these principles. A total of 19 countries responded to the first survey¹. This survey identified significant gaps in terms of the provision of care in haemophilia within each country. The survey was repeated in 2012² with 35 countries responding and again in 2015³ with 37 countries. Over these six years, with the significant increase in countries reporting a clearer picture of these disparities emerging. Whilst there have been increases in the availability of clotting factor concentrates (CFC), there are still 13 countries who remain below the EDQM minimum recommendations for CFC4, with further 5 countries unable to provide data on CFC use due to lack of access to data.

The picture developing shows that countries with a highly organised system for delivering haemophilia care is capable of producing a level of care beyond their economic constraints. These are countries with good registries that record all people with haemophilia (mild, moderate, severe), have patient and clinician involvement in all aspects of care including decision-making on haemophilia care and choosing haemophilia treatment products. These countries also include a well-defined network of comprehensive care centres and haemophilia treatment centres to treat patients effectively and optimise the use of CFC's to maximise the benefits for patients.

¹ O'Mahony B, Noone D, Giangrande PLF, Prihodova L. Haemophilia care in Europe: A survey of 19 countries. *Haemophilia*. 2011;17(1):35-40. doi:10.1111/j.1365-2516.2010.02362.x.

² O'Mahony B, Noone D, Giangrande PLF, Prihodova L. Haemophilia care in Europe - a survey of 35 countries. *Haemophilia*. 2013;19(4). doi:10.1111/hae.12125.

³ O'Mahony B, Savini L, Hara JO, Bok A. Haemophilia care in Europe - A survey of 37 countries. *Haemophilia*. 2017;23(4):e259-e266. doi:10.1111/hae.13263.

⁴ Giangrande PLF, Peyvandi F, O'Mahony B, et al. Kreuth IV: European consensus proposals for treatment of haemophilia with coagulation factor concentrates. *Haemophilia*. 2017;23(3):370-375. doi:10.1111/hae.13211.

Respondent countries

Country	2009	2012	2014
Belgium	✓	✓	✓
Bulgaria	✓	✓	✓
Czech Republic	✓	✓	✓
Germany	✓	✓	✓
Hungary	✓	✓	✓
Ireland	✓	✓	✓
Latvia	✓	✓	✓
Lithuania	✓	✓	✓
Netherlands	✓	✓	✓
Poland	✓	✓	✓
Portugal	✓	✓	✓
Romania	✓	✓	✓
Russia	✓	✓	✓
Slovak Republic	✓	✓	✓
Sweden	✓	✓	✓
Switzerland	✓	✓	✓
United Kingdom	✓	✓	✓
Albania		✓	✓
Armenia		✓	✓
Austria		✓	✓
Azerbaijan		✓	✓
Denmark		✓	✓
Finland		✓	✓
Greece		✓	✓
Italy		✓	✓
Macedonia		✓	✓
Serbia		✓	✓
Slovenia		✓	✓
Spain		✓	✓
Turkey		✓	✓
Ukraine		✓	✓
Estonia			✓
Georgia			✓
Israel			✓
Kyrgyz Republic			✓
Montenegro			✓
Norway			✓
Bosnia-Herzegovina	✓	✓	
France	✓	✓	
Belarus		✓	
Croatia		✓	
Cyprus			
Iceland			
Luxembourg			
Moldova			