Hæmophilia Care in Europe | Heat Map: Results of the survey of 43 countries

This heat map gives you a quick glimpse into how countries perform when providing care and treatment for haemophilia and other rare bleeding disorders. It reflects the 2018 Survey's results on Comprehensive Haemophilia Care by the European Haemophilia Consortium. Blue represent values that either meet or exceed international standards. Orange represent values that need to improve while **yellow** show some efforts in the good direction, but that still need work.

Legend

POSITIVE NEGATIVE

NR **NO DATA**

Country		Hungary	Ireland	Sweden	lceland	United Kingdo	d Ita	ly Slov	enia Fii	nland G	ermany	Belgium	Slovakia	Switzerland	France	Russia	Norway	Poland	Lithuania	Portugal	Czech Republic	Croatia	Estonia	Greece	Latvia	Belarus	Serbia	Bulgaria	Macedonia	Romania	Georgia	Montenegro	Azerbaijan	Albania	Ukraine	Moldova	Armenia	Kyrgyzstan	Austria	Bosnia ar Herzegovi	Denmark	Israel	Netherlands	Spain	Turkey
																							<< Above F	actor VIII roc	ommendation	Bolow Fac	stor VIII rocom	nmendation >											No rospo	nse on Fact					
International units	Factor VIII	12.63	10.01	10.07	9.90	0 75		67 0	42	7 00	7.00	7.02	7.67	7.07	7.05	7.04	6.73	6 60	6 47	6.31	6.21	4.90	4.81	4.37	4.24	3.79	3.34	2 00	200	2 20	2 20	2.02	4 72	1 57	4 42	4 42	0.62	0.27	NR NR	IISE OII FACE	ND	ND	ND	ND	NR
per capita			10.91	10.07	9.90	0.75	0.0	0.	43	7.99	7.90	7.93	7.07	7.07	7.05	7.04	0.73	0.09	0.47	0.31	0.21	4.90	4.01	4.37	4.24	3.79	3.34	3.00	2.00	2.29	2.29	2.02	1.72	1.57	1.13	1.12	0.63	0.27		NE	INIX	NE	INIX	INIX	
	Factor IX	NR	2.43	2.03	NR	1.22	2 1.0	04 0.	56	2.20	0.83	0.96	0.58	0.99	1.21	0.78	0.59	0.99	1.28	0.85	0.70	1.30	0.36	0.52	0.37	NR	0.44	0.36	0.48	0.27	0.40	0.29	NR	0.14	0.22	0.06	0.06	0.02	NR	NR	NR	NR	NR	NR	NR
Organisation	Comprehensive Care Centres (CCC's)	Yes	Yes	Yes	No	Yes	Ye	es Y	es	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	No	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
of care	Haemophilia Treatment Centres	Yes	Yes	No	Yes	Yes	Ye	es N	lo	Yes	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes	Yes
	National Haemophilia Council or Co-ordinating Group	No	Yes	Yes	No	Yes	N	lo N	lo	No	No	No	Yes	No	Yes	No	Yes	Yes	No	Yes	Yes	No	No	No	No	No	Yes	Yes	Yes	Yes	Yes	No	Yes	No	No	NR	No	No	No	Yes	No	No	Yes	NR	Yes
	Number of groups in decision-making on haemophilia care	2	3	2	2	3	3	3	2	2	3	3	3	2	3	3	3	3	3	3	3	2	1	3	2	1	3	2	2	2	3	2	3	3	2	NR	2	3	3	1	3	2	3	NR	NR
	Number of groups choosing haemophilia treatment products	2	3	2	2	3	3	3	2	2	2	3	3	1	3	3	3	2	3	3	2	2	1	1	1	2	3	2	2	2	3	2	2	2	3	NR	2	2	1	1	3	3	1	NR	NR
	National Tender for procurement of factor concentrates	Yes	Yes	No	Yes	Yes	N	o Y	es	No	No	No	Yes	No	No	Yes	Yes	Yes	No	Yes	No	No	Yes	No	No	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes	NR	Yes	Yes	No	Yes	Yes	No	Yes	No	No
Treatment	Home Treatment	Yes	Yes	Yes	Yes	Yes	Ye	es Y	95	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	NR	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	% of people with haemophilia using home treatment	76-100%	76-100%	76-100%	76-100	% 76-100	0% 76-1	00% 51-7	75% 76-	-100% 70	6-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	10-50%	76-100%	76-100%	76-100%	76-100%	76-100%	51-75%	76-100%	10-50%	76-100%	51-75%	10-50%	<10%	<10%	NR	<10%	<10%	76-100%			76-100%	76-100%	76-100%	51-75%
g	Treatment delivered to the patient's home		Unknown	Some	No	Unkno	wn So	me N	lo S	Some	Some	Some	No	Unknown	Some	Some	Unknown	Some	Some	No	No	Some	Some	Unknown	No	No	No	No	No	No	Some	No	Unknown	No	No	NR	No	No	NR	No	Unknown	No	Some	Some	Unknown
	Prophylaxis treatment availability	Yes	Yes	Yes	Yes	Yes	Ye	es Y	es	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Some	Yes	Yes	Some	Yes	Children	Children	Some	Some	Yes	Children	No	Some	No	Some	No	Yes	Some	Yes	Yes	Yes	Yes	Some
	Children currently on prophy (%)	76-100%	76-100%	76-100%	76-100	% 76-100	0% 76-1	00% 76-1	00% 76-	-100% 76	6-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	51-75%	76-100%	76-100%	76-100%	51-75%	76-100%	76-100%	76-100%	76-100%	26-50%	76-100%	1-25%	0	26-50%	0	0	0	76-100%	76-1009	% 76-100%	76-100%	76-100%	76-100%	76-100%
	Adults currently on prophy (%)	51-75%	76-100%	76-100%	76-100	% 76-100	0% 76-1	00% 51-7	75% 51	1-75% 5	51-75%	76-100%	51-75%	76-100%	51-75%	51-75%	76-100%	76-100%	51-75%	51-75%	51-75%	26-50%	26-50%	26-50%	76-100%	0	26-50%	1-25%	1-25%	1-25%	1-25%	51-75%	1-25%	0	1-25%	0	0	0	51-75%	51-75%	6 51-75%	26-50%	76-100%	26-50%	51-75%
	Access to ITI (% of people with inhibitors)	76-99%	100%	100%	100%	100%	% 76-9	99% 10	0% 1	100%	100%	100%	100%	100%	100%	76-99%	100%	100%	1-25%	76-99%	100%	1-25%	100%	76-99%	76-99%	26-50%	51-75%	1-25%	0	0	1-25%	0	0	0	1-25%	0	0	0	100%	0	100%	100%	100%	100%	
Access to	Emergency medicine and acute surgery	Yes	Yes	Yes	Yes	Yes	Some	times Y	es	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	NR	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Sometimes	Yes	NR	Yes	Yes	NR		es Sometimes	Yes	Yes	NR	NR
specialist services		Yes	Yes	Yes	Yes	Yes	Some	times Y	es	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	NR	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	NR	Yes	Yes	NR	Yes		Yes	Yes	NR	NR
	Infectious disease specialists (especially HIV)	Sometimes	Yes	Yes	Yes	Yes	Some	times Y	es	Yes	Yes	Yes	Yes	Sometimes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	NR	Yes	Sometimes		Sometimes		Sometimes	Yes	Never	Yes	Yes	Yes	Sometimes	NR		Sometimes	NR	Sometime		Yes	Yes	NR NR	
	Hepatology	Sometimes	Yes	Yes	Yes	Yes	Some	times Y	es	Yes	Yes	Yes	Yes	Sometimes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	NR	Yes	Sometimes		Sometimes		Sometimes	Yes	Never	Sometimes	Yes	Yes	Never	NR		Sometimes	NR	Sometime		Yes	Yes	NR	
	Rheumatology	Never	Yes	Sometime	s Yes	Yes	Some	times Ne	ver	Yes	Yes	Yes	Yes	Sometimes	Yes	Never	Yes	Yes	Yes	Yes	Yes	Yes	NR		s Sometimes	Sometimes	Sometimes	Sometimes	Never	Yes	Never	Sometimes	Yes	Sometimes	Never	NR 		Sometimes	NR	Yes		Sometimes	Yes	NR	NR
	Orthopaedics	Sometimes	Yes	Yes	Yes	Yes		(;)	es	Yes	Yes	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	NR	Yes	Yes	Sometimes		Yes	Yes	Yes	Sometimes	0 "	Yes	Never	Yes	NR	Yes	Yes	NR	Sometime		Yes	Yes	NR	NR
	Physiotherapy	Sometimes	Yes	Yes	Sometim	es Yes			es	Yes	Yes	Yes	Yes	Yes	Sometimes	Yes	Yes	Sometimes	Yes	Sometime	Yes	Yes	NR	Yes	Yes	Sometimes		Sometimes	Yes	Yes	Yes	Sometimes	Yes		Sometimes	NR		Sometimes	NR	Sometime		Yes	Yes	NR	NR
	Dentistry Obstatisies and Company of the Company o	Never	Yes	Yes	Never	Yes	Some		es	Yes	Yes	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Sometime	Yes	Yes	NR		Sometimes	Sometimes		Yes	Yes	Yes	Never	Sometimes	Yes	Yes	Never	NK	Yes	Yes	NR NR	Yes			Yes	NK	NR NR
	Obstetrics and Gynaecology Genetics	Never	Voc	Voc	Voc	Yes Yes			28	Voc	Voc	Voc	Voc	Sometimes	Yes Yes	Sometimes	Voc	Comotimo	Voc	Comotimo	Voc	Voc	NR	Yes	Sometimes		Sometimes Sometimes		Voc	Comotimos	Never	Comotimos	Yes	Sometimes	Never	NID	Yes Never	Sometimes	NIC	Yes Never		Voc	Yes	NIC	NR
	Social and psychological support	Never Never	Vec	Vec	Sometim	es Sometir			ver	Vec So	metimes	Vec	Vec	Sometimes	Sometimes	Never	Vec	Sometimes	Vec	Sometime	Sometimes	Vec	NR	Yes	Sometimes Sometimes		Sometimes		Vec	Vec	Never	Sometimes	Sometimes	Sometimes	Never	ND	Yes	Never	NR		es Sometimes	Vec	Ves	ND	NR
	Pain management	Never	Vac	Ves		es Sometir			ver	Vec	Vec	Vac	Vec	Sometimes	Sometimes	Never	Sometimes	Vac	Vec	Sometime			NR		s Sometimes		Sometimes		Never	Ves	Vee	Sometimes	Yes		Sometimes	NR		Yes	NR		Sometimes		Ves	NR	NR
	General surgery	Sometimes	Yes	Yes	Yes		mes Some		25	Yes	Yes	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	NR		Sometimes			Sometimes	. 10 . 0.	Yes	Sometimes		Yes	Sometimes		NR	Yes	Yes	NR		es Sometimes		Yes	NR	NR
	Urology	Never	Yes	Yes		Sometin			es	Yes	Yes	Yes	Yes	Sometimes	Yes	Sometimes	Yes	Yes	Yes	Sometime	Yes	Yes	NR		Sometimes			s Sometimes							Sometimes	NR	Sometimes		NR		es Sometimes		Yes	NR	NR
	- 37																																										1		
Share of Expected	Haemophilia A	92%	127%	65%	193%	119%	68	10	3%	44%	46%	87%	96%	69%	91%	44%	62%	64%	53%	53%	88%	101%	76%	80%	67%	74%	65%	307%	11%	433%	439%	4%	406%	4%	687%	72%	32%	38%	117%	14%	23%	13%			
Bleeding Disorder Prevalence	Haemophilia B	77%	160%	57%	19%	87%	48	3% 48	3%	41%	28%	69%	46%	45%	69%	25%	56%	37%	28%	36%	43%	69%	25%	56%	45%	57%	40%	109%	18%	186%	286%	1%	162%	2%	400%	21%	11%	14%	68%	7%	20%	7%			
Frevalence	von Willebrand Disease	15%	29%	2%	14%	16%	5 5	% 9	%	10%	5%	17%	12%	0%	3%	1%	11%	5%	11%	0%	8%	5%	8%	10%	6%	3%	4%	3%	1%	9%	6%	0%	7%	0%	17%	0%	0%	0%	0%	0%	2%	0%			
Haama-bii-	Deams derived factor consentrate	Abresie	Doreh	Danak	Mayer	Camaa ti	maa . Cawaa	times D-	roly D	Poroh	Λ huove	Ahvorra	Ahverra	Donah	Aberra	Δ1,,,,,,,	Doroh	Abresie	Λ h	Ahrrania	Almania	Abresie	Almania	Danahi	Ahararra	Ahvers	Λh	Alverva	ΛΙ	Ah.,,-	Abresie	Aharara	Λ h · · σ · · σ	Ahrene	Ahararra	Dorek	Abresie	Densh	Abusa	Cometime	oo Danaki	Almania	Danahi	Ahararra	Ahuova
Haemophilia	Pasma-derived factor concentrate Recombinant factor concentrate	Always	Rarely	Always	Never	Sometin	mes Some	ave Ali	ely R	lwove	Always	Always	Somotimes	Alwaya	Always	Always	Always	Aiways	Always	Always	Always	Aiways	Always	Always	Aiways	Always	Always	Always	Paraly	Always	Paralys	Always	Perely	Porch	Aiways	Rarely	Always	Rarely	Always	Sometime	es Kareiy	Always	Always	Always	Always
replacement therapy	Plasma	Rarely Never	Never	Never	Nover	Nove	r No	ays AlW	ver N	lever	Never	Never	Never	Never	Never	Never	Always	Never	Never	Nover	Never	Never	Paraly	Paraly	Nover	Never	Never	Never	Never	Never	Parely	Never	Parely	Parely	Sometimes	Never	Rarely	Rarely	Novor	Nover	Nover	Never	Never	Never	Always
шетару	Cryoprecipitate	Never	Never	Never	Never	Neve	ar Ne	ver Ne	ver N	Never Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Rarely	Never	Never	Never	Never	Rarely	Never	Rarely	Rarely	Sometimes	Rarely	Never	Always	Never	Sometime	Never	Never	Never	Never	NR
	o. y opi o oipituto	146461	INCACI	INCVE	140 401	Neve	. INC	· Si INC	. 51	10101	140 4 61	140701	140701	146761	INCVCI	140461	INCACI	Nevel	146761	IACACI	INCVCI	INCVCI	INCVCI	TVCVCI	Nevel	Talely	TVCVCI	INCVE	140 4 61	140761	Tarely	INCVE	MaiGly	raiciy	Comedines	raiciy	140 (61	Aways	146461	Joineuill	INGVE	INCACI	NOVE	INCVGI	1.41.7
VWD	Plasma-derived factor concentrate	Rarely	Always	Always	Always	Alway	/s Rai	rely Alw	ays Al	lways A	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Rarely	Always	Always	Sometimes	Always	Always	Always	Rarely	Always	Rarely	Never	Always	Rarely	Always	NR	Always	Rarely	Always	Sometime	es Always	Always	Sometimes	Always	NR
replacement	DDAVP	Rarely	Always	Always	Always	Alway	/s Alw	ays Ra	rely Al	lways A	Always	Always	Rarely	Always	Always	Never	Always	Sometimes	Rarely	Always	Rarely	Rarely	Sometimes	Always	Always	Rarely	Always	Always	Never	Rarely	Rarely	Rarely	Always	Always	Never	NR	Sometimes	Rarely	NR	Never	Always	Rarely	Sometimes	NR	NR
therapy	Plasma	NR	Never	Never	Never	Rare	ly Rai	rely Ne	ver N	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Rarely	Never	Never	Rarely	Never	Never	Never	Never	Always	Never	Always	Rarely	Sometimes	NR	Sometimes	Always	Never	Never	Never	Never	Sometimes	Never	NR
	Cryoprecipitate	NR	Never	Never	Never	Rare	ly Rai	rely Ne	ver N	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Rarely	Never	Rarely	Always	Rarely	Always	Never	Always	Rarely	Never	NR	Never	Always	NR	Never	Never	Never	Never	NR	NR
		-																																									4		

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 2018. 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 hæmophilia 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

remain below the minimum recommended European standards after 10 years of improvement.

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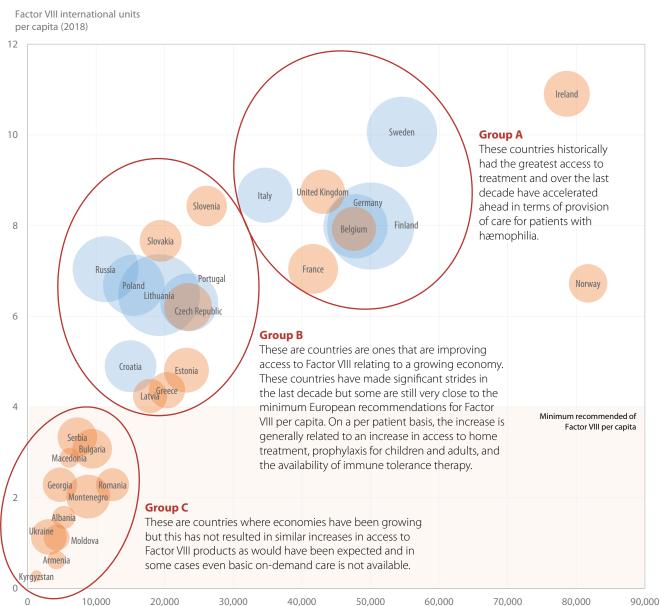
Rue de la loi 28

For countries that have reported in all four surveys, there is a positive trend in terms of access to Factor VIII products repre-

sented by Factor VIII per capita. Whilst all countries have increased the overall volumes, there are still some countries that



Over 60 000 IUs of Factor VIII use per registered patient Less than 60 000 IUs of Factor VIII use per registered patient



GDP per capita (USD 2018)

2021 EDITION

HÆMOPHILIA CAREINEUROPE



Survey of 43 countries

urope is a disparate continent with a wide range of economic conditions and health systems in individual countries. In 2008, the European principles of hæmophilia care were drafted by an interdisciplinary group of hæmophilia physicians with input from key

These principles are:

1. Establishment of a central hæmophilia organisation in each country with supporting local group

patient opinion leaders and endorsed by EHC and EAHAD.

- 2. National hæmophilia patient registries
- 3. A network of multidisciplinary comprehensive care centres and complementary hæmophilia treatment centres
- 4. Partnership of health care professionals and patients in the delivery of hæmophilia 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 hæmophilia 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 hæmophilia 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 hæmophilia care is capable of producing a level of care beyond their economic constraints. These are countries with good registries that record all people with hæmophilia (mild, moderate, severe), have patient and clinician involvement in all aspects of care including decision-making on hæmophilia care and choosing hæmophilia treatment products. These countries also include a welldefined network of comprehensive care centres and hæmophilia treatment centres to treat patients effectively and optimise the use of CFC's to maximise the benefits for patients.

2009 2012 2015 2018

Respondent countries for each survey

• • • •

Durguriu				
Czech Republic	•	•	•	•
Germany	•	•	•	•
Hungary	•	•	•	•
Ireland	•	•	•	•
Latvia	•	•	•	•
Lithuania	•	•	•	•
Netherlands	•	•	•	•
Poland	•	•	•	•
Portugal	•	•	•	•
Romania	•	•	•	•
Russia	•	•	•	•
Slovakia	•	•	•	•
Sweden	•	•	•	•
Switzerland	•	•	•	•
United Kingdom	•	•	•	•
Albania		•	•	•
Armenia		•	•	•
Austria		•	•	•
Azerbaijan		•	•	•
Bosnia and Herzegovina	•	•		•
Denmark		•	•	•
Finland		•	•	•
France	•	•		•
Greece		•	•	•
Italy		•	•	•
Macedonia		•	•	•
Norway		•	•	•
Serbia		•	•	•
Slovenia		•	•	•
Spain		•	•	•
Turkey		•	•	•
Ukraine		•	•	•
Croatia		•		•
Estonia			•	•
Georgia			•	•
Israel			•	•
Kyrgyzstan			•	•
Montenegro			•	•
Belarus				•
Iceland				•
Moldova				

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

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

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

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