

Haemophilia care in Europe - A survey of 37 countries

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Introduction: The European Haemophilia Consortium (EHC) is an international non-profit organization representing 45 national patients' organizations in Europe. Every 3 years, the EHC circulates a survey to its national member organizations to assess the state of haemophilia care.

Aim: The purpose of this exercise is to ascertain information about the organization of haemophilia care and treatment availability at national levels. Furthermore, the survey provides a basis from which the EHC are able to monitor the unmet need and stability of care/treatment access in the individual member countries.

Patients and Methods: Surveys are distributed to EHC member organizations in English and Russian. Patient organizations are encouraged to share the survey with local clinicians to ensure accuracy of responses. The data collected are in part consistent to provide a longitudinal overview for treatment access, but topical items are included such as ageing. Subsequently, completed surveys are transposed into a database for analysis and reporting.

Results: Thirty-seven responses were received from the 45 countries approached, representing an 82% response rate from members. Findings suggest increased access to treatment and some improvement in certain areas of care. However, access to treatment has declined or remained largely unchanged in some countries.

Conclusion: The survey has been a successful exercise in enabling a greater understanding of the current Haemophilia care landscape across Europe. However, there remain unmet needs in various aspects of patient care, and specific examples include psychosocial care and general preparedness for an ageing haemophilia population.

KEYWORDS

haemophilia, organization, specialist care, treatment

1 | INTRODUCTION

In 2008, an interdisciplinary group of haemophilia physicians drafted a document with input from key patient opinion leaders and clinical nurse specialists that outlined the European principles of haemophilia care.¹ The European Haemophilia Consortium (EHC) and the World Federation of Hemophilia (WFH) endorsed these principles. They were officially launched at the European Parliament in Brussels in January 2009. Since their launch, and every 3 years since, the

EHC has conducted surveys amongst its national haemophilia patient organization members to determine the extent to which these haemophilia principles are met in European countries. A total of 19 countries responded to the 2009 survey.² In 2010 and again in 2013, the European Directorate for the Quality of Medicines and Healthcare (EDQM), part of the Council of Europe, published reports on the optimal use of blood and blood products,³ which also contained specific recommendations for haemophilia. In April 2015, the Committee of Ministers of the Council of Europe adopted a resolution⁴ on principles

for haemophilia. Since 2012, the EHC has included the EDQM recommendations in its surveys. A total of 35 countries responded to the EHC's 2012 survey,⁵ and a total of 37 countries responded to the 2015 survey (Table S1).

2 | METHODS

Between November 2015 and April 2016, the EHC developed and sent out a questionnaire to 45 national haemophilia patient organizations from across Europe. Responses were received from 37 countries including from first-time respondent countries Estonia, Georgia, Israel, Kyrgyzstan, Montenegro and Norway. There were also a number of countries that took part in the 2012 survey but did not respond to the 2014 survey, and these were Croatia, France, Belarus, and Bosnia and Herzegovina. The national haemophilia patient organizations responded based on their own records and typically would have consulted clinicians and the national registry, where one exists. They were not asked to specify the sources of their data, as it is not practical to ascertain the precise sources of the information used by each national member organization in providing data for this survey. However, all information provided was given with the best available knowledge of the organizations. A greater degree of accuracy can be expected from countries where there is a national register, where this information is available to the national patient organization. Organizations were requested to supply information on factor usage for the calendar year 2014. The questionnaire consisted of 39 questions of which 30 questions examined the extent to which the European principles of care and the EDQM recommendations reflect the reality of haemophilia treatment and care in these countries; four questions examined cross-border access to haemophilia care; and five questions examined ageing and haemophilia. The countries that responded included 23 member states of the European Union (EU) and 14 non-EU countries (Table S1). The 37 countries covered a total of 45 116 patients with haemophilia A; 8514 patients with haemophilia B and 30 296 patients with von Willebrand's disease (VWD).

3 | RESULTS

3.1 | Organization of patient care

Of the 37 respondent countries, 18 stated that they have a National Haemophilia Committee/Council (NHC) or coordinating group that includes representatives from the treatment centres, patient organizations and the Ministry of Health (with one of them, the Czech Republic, responding that this group includes all representatives except from the Ministry of Health), while 19 do not have a NHC (Table S2). In 14 of the 18 countries that have such a group, the group has a formal role in advising or organizing haemophilia care nationally. Compared to the 2012 survey, we note that the following countries have developed a NHC or coordinating group: Azerbaijan, Georgia Kyrgyzstan, Macedonia, Montenegro and Romania. Additionally, we also note that six countries lost their NHC since the last survey. These were Finland, Germany, Greece, Italy, Lithuania and Spain.

3.2 | Haemophilia treatment centres and national patient registries

Of the 37 respondent countries, 23 stated that they have a recognized haemophilia treatment centre (HTC) with responsibility for areas such as coordination or a registry, while 14 countries do not. Of the 37 respondent countries, 16 stated that they have a system of classification for HTCs, while 21 countries do not. Of these 16 countries, 11 countries have a recognized HTC with coordination or registry responsibility, namely Armenia, Belgium, Bulgaria, Czech Republic, Georgia, Ireland, Norway, Poland, Slovakia, Sweden and the UK.

A total of 29 countries have a national patient registry, and eight countries do not. The countries that do not yet have a registry are Estonia, Kyrgyzstan, Lithuania, Macedonia, the Netherlands, Portugal, Sweden and Ukraine. In terms of the management of the registry, in 13 countries, the haemophilia centre is involved, in another 13 countries, the haemophilia patient organization is involved, in seven countries, the government is involved, in four countries, the national organization (NHC or coordinating group) is involved, in one country a teaching hospital is involved and in 11 countries other institutions are involved. In 15 countries, there are more than one organization involved in the management of the registry. Of the 37 respondent countries, 29 reported that they have comprehensive care centres (CCCs provide a comprehensive level of care, as part of their role receive referrals from tertiary centres and HTCs provide routine care and usually operate in conjunction with a CCC). Eight countries stated that they do not have CCCs, namely Armenia, Estonia, Kyrgyzstan, Latvia, Macedonia, Montenegro, Spain and Ukraine. Of the 11 countries that previously reported in 2012 that they did not have CCCs, six have since developed such centres, namely Albania, Bulgaria, Hungary, Lithuania, Portugal and Serbia. A total of 28 countries stated that they have HTCs. Those that state that they do not have HTCs are Armenia, Denmark, Estonia, Kyrgyzstan, Lithuania, Montenegro, the Netherlands, Norway and Sweden. Four countries stated that they have neither CCCs nor HTCs, namely Armenia, Estonia, Kyrgyzstan and Montenegro. The definition of CCC and HTC follows the concepts developed by the European Haemophilia Network (EUHANET).

In relation to national decision-making on haemophilia care, 32 countries stated that the Health Ministry plays a significant role, of which eight countries also stated that the government plays a significant role (Albania, Armenia, Hungary, Italy, Norway, Russia, Sweden and Switzerland) and four countries also stated that the Social Affairs Ministry plays a significant role (Finland, Germany, Romania and Russia). A total of five countries stated that patients play a significant role (Macedonia, Romania, Slovakia, Slovenia and the UK), whereas 20 countries stated that the haemophilia patient organizations play a significant role, and 27 countries stated that clinicians play a significant role. A total of 16 countries reported shared decision-making in national haemophilia care between patients/patient organizations, clinicians and government bodies (Armenia, Austria, Denmark, Germany, Ireland, Macedonia, the Netherlands, Poland, Romania, Russia, Serbia, Slovakia, Slovenia, Sweden, Turkey and the UK).

In relation to choice of haemophilia treatment products, 27 countries responded; four (Hungary, Macedonia, Sweden and Switzerland) stated that the government is involved in the choice; 26 stated that the Health Ministry is involved and one (Sweden) stated that the regional government is involved. A total of 19 countries stated that hospitals or CCCs are involved in the choice whereas 23 countries stated that clinicians are involved in the selection of treatment products (in 12 countries, both hospitals and clinicians are involved, namely Bulgaria, Denmark, Finland, Germany, Hungary, Italy, the Netherlands, Norway, Portugal, Romania, Slovakia and Sweden). A total of six countries stated that patients are involved (Greece, Portugal, Slovakia, Sweden, Turkey and Ukraine), whereas nine countries stated that patient organizations are involved (Georgia, Ireland, Portugal, Russia, Serbia, Slovakia, Slovenia, Spain and the UK). In Portugal and Slovakia, both patients and haemophilia patient organizations are involved. A total of 15 countries have a national procurement or tender committee and seven countries listed additional stakeholders who are involved in product choice (eg health insurance agencies).

3.3 | Home treatment

It is widely accepted that home treatment and home delivery should be available in each country to facilitate immediate and effective treatment. Home treatment is available in 32 of the 37 countries (Table S3) and is delivered directly into the patient's home in six countries (Austria, Greece, Ireland, Switzerland, Turkey and the UK) and on occasion delivered into the patient's home in 11 other countries (Azerbaijan, Denmark, Estonia, Finland, Italy, the Netherlands, Norway, Poland, Russia, Slovakia and Sweden). Home treatment is not available in Albania, Armenia, Kyrgyzstan, Montenegro and Ukraine. In one country (Azerbaijan), <10% of people with haemophilia (PWH) use home treatment. In two countries (Romania and Serbia), between 10% and 50% of PWH use home treatment and in four countries (Bulgaria, Estonia, Portugal and Turkey), between 51% and 75% of PWH use home treatment. In 24 countries, between 76% and 100% of PWH use home treatment (Table 1).

3.4 | Prophylaxis

It is commonly accepted that prophylaxis is the optimal treatment strategy for patients with severe haemophilia and absence of its availability is associated with long-term joint destruction and high annualized bleed rates. The reported proportions of patients with access to prophylactic regimens are based on the severe patient population. The EHC survey found that in 17 countries, all PWH reportedly have access to prophylaxis. In nine countries, some PWH have access and in seven countries only children have access to prophylaxis (Table S3).

In total, children have access to prophylaxis in 30 of 37 countries (Table S3). In 26 countries, 76%-100% of children have access, in two countries (Romania and Serbia) 51%-75% and in another two (Azerbaijan and Ukraine) 26%-50% of children have access. Three countries (Denmark, Italy and the Netherlands) did not report these data.

TABLE 1 Changes in access to home treatment, immune tolerance induction (ITI) and prophylaxis in both children and adults in responding countries between 2012 and 2015

	Home treatment	ITI	Prophylaxis in children	Prophylaxis in adults
AT			↑	↑
AZ		↑	↑	
BE				↑
BG	↑	↑	↑	
CZ				↑
ES				↑
HU	↑			
IE				↑
LV			↑	↑
LT				↑
NL				↑
PL				↑
PT		↑	↑	↑
RO	↑		↑	
RS		↑	↑	
RU	↑	↑	↑	
SI	↑		↑	↑
TR			↑	↑
UA	↓	↓	↑	

↑ increase in access; ↓ decrease in access - countries with no change were not included in the table.

Regarding adults, in seven countries, 76%-100% of adults have access to prophylaxis (Belgium, Ireland, Latvia, the Netherlands, Norway, Slovenia and Sweden), whereas in five countries, 51%-75% of adults have access (Austria, Finland, Germany, Poland and UK). In nine countries, 26%-50% of adults have access and in eight countries, 1%-25% of adults have access to prophylaxis. Denmark and Italy did not report these data.

In Albania, Armenia, Georgia and Kyrgyzstan, neither children nor adults have access to prophylaxis and in these countries, home treatment is also not available. In addition to these countries, adults in Romania and Ukraine have no access.

3.5 | Immune tolerance induction

Seven countries reported that immune tolerance induction (ITI) is never available to PWH who have inhibitors (Albania, Armenia, Kyrgyzstan, Macedonia, Montenegro, Romania and Ukraine). In 15 countries, ITI is available to all PWH with inhibitors, in four countries it is available to 76%-100% (Austria, Hungary, Poland and Sweden), in two countries it is available to 51%-75% (Portugal and Russia) and in seven countries it is available to 1%-25% (Azerbaijan, Bulgaria, Estonia, Georgia, Lithuania, Serbia and Turkey) (Table S3). Italy and Latvia did not report these data.

3.6 | Specialist care

To assess the availability of comprehensive care, countries were asked the degree of access to a number of specialty services, including emergency medicine and acute surgery, paediatrics, infectious diseases, hepatology, rheumatology, orthopaedics, physiotherapy, dentistry, obstetrics and gynaecology, genetics, social and psychological support, pain management, general surgery and urology (Table 2). Seven countries stated that PWH have access to all of these services all of the time (Austria, Belgium, Finland, Ireland, the Netherlands, Norway and Switzerland).

The most available specialty services reported by 37 countries are paediatrics (34), emergency medicine and acute surgery (31), orthopaedics (30), infectious disease specialists (26) and general surgery (26). The least available reported specialty services are pain management (16), rheumatology (16) and social and psychological support (13) - this has been the least available service since we started our survey in 2009. Physiotherapy is consistently available in 25 countries and sporadically available in another 10 countries. Patients have consistent access to dental services in 24 countries, sporadic access in eight countries and rarely or never have access to dental services in four countries (Albania, Estonia, Georgia, Hungary and Kyrgyzstan). Women in 24 countries have systematic access to obstetricians and/or gynaecologists, in 10 countries, they have sporadic access and in two countries (Georgia and Kyrgyzstan), they have almost no access. Hepatology services are consistently available in 23 countries, sporadically available in 10 and rarely available in three. Patients are able to regularly consult urologists in 22 countries, sporadically in nine countries, rarely in two and in four countries never have this service available. A total of 21 countries offer regular genetic services, 10 countries offer sporadic access and six countries do not have this service. Patients in Kyrgyzstan rarely or never access any single comprehensive care service in their country. Patients in Ukraine never have access to infectious disease specialists. Patients in Albania have no dental services available (Table S4).

3.7 | Treatment of haemophilia

In terms of access to treatments, 19 countries reported that both plasma-derived and recombinant factor concentrates are always available. A total of 29 countries stated that recombinant factor concentrates are always available; of those, 10 countries reported that they rarely have plasma-derived factor concentrates available. A total of 26 countries state that plasma-derived factor concentrates are always available; of those, five countries stated that they rarely have recombinant factor concentrates available and one country (Montenegro) stated that it never has access to recombinant factor concentrates. Estonia, Kyrgyzstan and Ukraine reported that plasma and cryoprecipitate are always used. In six countries, cryoprecipitate is reportedly used infrequently (Albania, Azerbaijan, Georgia, Romania, Russia and Serbia) and in 10 countries, plasma is reportedly used infrequently (Tables 3 and S5).

3.8 | Treatment of von Willebrand's Disease

A total of 30 countries reported that they always have plasma-derived factor concentrates available for the treatment of VWD, whereas four countries (Albania, Kyrgyzstan, Montenegro and the Netherlands) reported rarely having access to plasma-derived factor concentrates, and Latvia and Macedonia reported never using plasma-derived factor concentrates to treat VWD. With regard to desmopressin (DDAVP), 21 countries reported always having DDAVP available for the treatment of VWD, whereas nine countries reported rarely having DDAVP available and four countries reported never having DDAVP available for treatment (Armenia, Czech Republic, Macedonia and Russia; Table 3 and S5).

3.9 | Per capita factor use

Of 37 respondent countries, 27 reported factor VIII and 25 reported factor IX use per capita for 2014 (Table S3). IU per capita figures from Macedonia and Serbia were provided directly by the patient organization; all others were calculated by EHC. Data provided by the Italian organization were from 2013.

Regarding FVIII consumption, of the 23 countries that responded on this point in both 2011 and 2014 surveys (Table 4 and Figure S1), 22 countries show between a small (3 per cent in Greece) to significant (107 per cent in Turkey) increase in per capita FVIII consumption. In Portugal FVIII use per capita went down by 1% between 2011 and 2014. The same question was asked in the EHC's 2008 survey² and 14 countries submitted these data in all three surveys. The responses (Figure 1) show that while six countries either slightly reduced or maintained their FVIII IU per capita between 2008 and 2011, eight countries increased it in that timeframe and all countries increased their FVIII per capita consumption between 2008 and 2014.

Regarding FIX consumption, of the 21 countries that responded on this point in both 2011 and 2014 surveys (Table 4, Figures S2 and S3), 14 countries show between a small (1.6 per cent in the UK) to very significant (1344 per cent in Albania) increase in per capita FIX consumption. However, in seven countries, FIX use per capita went down between 6 and 44 per cent (Azerbaijan, Germany, Greece, Ireland, Portugal, Romania and Slovakia).

3.10 | Factor use per capita compared with GDP

Using World Bank⁷ gross domestic product (GDP) figures as a measure of economic standing, the countries that underperform in access to FVIII per capita are Albania, Romania, Montenegro, Azerbaijan, Latvia and Switzerland and in access to FIX per capita, almost all countries underperform with the exceptions of Macedonia and Ireland (Figures S4 and S5).

Data from the 23 countries that responded both in 2012 and 2015 on FVIII use per capita, set against World Bank GDP figures for the same reported years, show a general improvement of FVIII consumption compared with GDP in most countries (Table S6 and Figure S6).

TABLE 2 Changes in access to specialist care in Europe between 2012 and 2015

	Emergency medicine and acute surgery		Paediatrics		Infectious disease specialists		Hepatology		Rheumatology		Orthopaedics		Physiotherapy		Dentistry		Obstetrics and gynaecology		Genetics		Social and psychological support		Pain management		General surgery		Urology		
AL	↑																												
AM																													
AZ			↑																										
BG	↓																												
CH																													
CZ																													
DE																													
DK	↑																												
ES																													
FI																													
HU																													
IT	↓																												
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PT																													
RO																													
RS																													
RU	↑																												
SI																													
SK																													
TR																													
UA	↑																												
UK																													

↑, increase in access since 2012; ↓, decrease in access since 2012. Countries are listed using ISO 3166-1 alpha-2 codes.

TABLE 3 Changes in treatment use for haemophilia and von Willebrand's disease (VWD) in Europe between 2012 and 2015

	Treatment for haemophilia				Treatment for VWD			
	Plasma	Cryoprecipitate	Plasma-derived factor concentrates	Recombinant factor concentrates	Plasma	Cryoprecipitate	Plasma-derived factor concentrates	DDAVP
AL		↓	↑	↑			↑	
AM	↓	↓	↑	↑		↓	↑	↓
AZ				↓			↑	
BE			↑					
CH	↑				↑			
CZ				↑				↓
DE	↑				↑			
EL			↓					
ES			↓					
IE			↑					
LT							↑	
LV							↓	
MK					↓		↓	
NL			↓				↓	
PL				↑				
RO	↑	↑		↓				
RS	↑	↑		↑	↑	↑		
RU	↓			↑				
SE			↓					↑
SI			↓		↓			↑
SK								↑
TR								↑
UA	↑	↑	↑	↑	↑		↑	↑
UK	↑				↑	↑		

↑, increase in use since 2012; ↓, decrease in use since 2012.

Countries are listed using ISO 3166-1 alpha-2 codes.

Data from the 21 countries that responded both in 2012 and 2015 on FIX use per capita, set against World Bank GDP figures for the same reported years, show little improvement of FIX consumption compared with GDP with the exception of Turkey and Macedonia (Table S6 and Figure S7).

3.11 | Cross-border health care

The EHC asked its national patient organizations whether, to the best of their knowledge, any of their members received haemophilia treatment in another European country. Of the 37 respondent countries, six countries responded that their patients have sought treatment and care in another country (Georgia, Ireland, Norway, Romania, Serbia, Slovakia). Conversely, 11 national patient organizations reported being aware of patients coming from other countries to seek treatment and care in their country (Czech Republic, Estonia, Finland, Georgia, Greece, Ireland, Israel, Norway, Slovakia, Sweden and Switzerland).

3.12 | Ageing

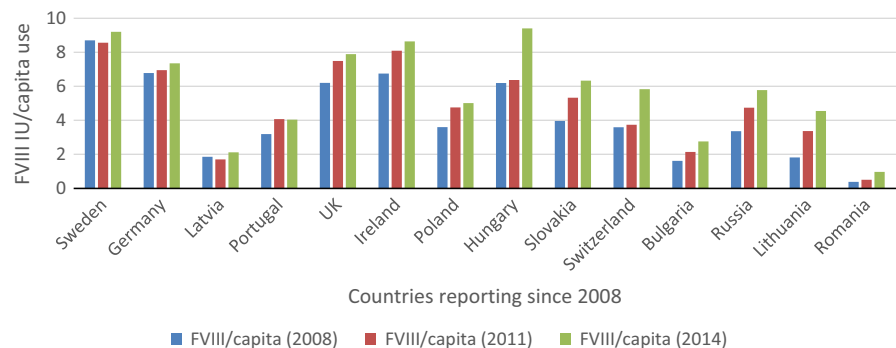
Regarding preparedness for supporting an ageing haemophilia population, of 37 respondent countries, six countries reported being aware of specific clinical services for ageing PWH (Belgium, Greece, the Netherlands, Serbia, Sweden, Switzerland); eight countries reported having guidelines for managing cardiovascular disease in older PWH (Austria, Belgium, Georgia, Israel, the Netherlands, Norway, Spain, UK); 16 countries reported being aware of educational programmes for patients or physicians on the healthcare issues of older PWH; and 21 countries reported that their patients or centres had raised concerns about the provision of care for older adults with haemophilia.

4 | DISCUSSION

The 2015 survey results show a general increase in per capita FVIII use in the past 3 years, ranging between three per cent and 107 per

TABLE 4 Changes in per capita use of FVIII and FIX between 2011 and 2014

	FVIII use per capita			FIX use per capita			GDP 2011	GDP 2014
	2011	2014	Change in use (%)	2011	2014	Change in use (%)		
AL	0.40	0.46	+15	0.016	0.231	+1344	10 209	11 307
AZ	1.44	1.84	+28	0.218	0.204	-6	15 754	17 608
BE	5.45	NR	NA	NR	NR	NA	41 249	44 747
BG	2.14	2.76	+29	0.134	0.189	+41	15 676	17 406
CH	3.74	5.83	+56	0.688	0.951	+38	55 919	61 282
CZ	3.59	5.17	+44	NR	NR	NA	28 797	32 386
DE	6.95	7.35	+6	1.017	0.850	-16	42 692	46 700
DK	6.17	NR	NA	1.247	NR	NA	44 808	47 100
EE	NR	3.22	NA	NR	0.232	NA	24 543	28 568
EL	3.61	3.72	+3	0.599	0.485	-19	26 627	26 851
FI	NR	7.79	NA	NR	1.426	NA	37 457	40 152
GE	NR	1.46	NA	NR	0.162	NA	7315	9216
HU	6.37	9.40	+48	0.495	0.606	+22	22 729	25 517
IE	8.09	8.64	+7	2.661	2.468	-7	45 477	51 311
IT	6.10	8.20	+34	0.825	1.099	+33	36 347	36 294
LT	3.37	4.55	+35	0.615	0.862	+40	22 845	28 067
LV	1.70	2.12	+25	0.216	0.311	+44	19 741	23 884
ME	NR	1.48	NA	NR	0.158	NA	14 472	15 410
MK	1.76	3	+70	0.462	0.800	+73	11 648	13 477
PL	4.76	5.01	+5	0.528	0.676	+28	22 850	25 730
PT	4.07	4.04	-1	0.633	0.538	-15	26 780	28 893
RO	0.51	0.97	+90	0.187	0.104	-44	18 095	20 797
RS	1.22	2.04	+67	0.101	0.240	+138	12 968	13 806
RU	4.74	5.78	+22	0.493	0.682	+38	24 074	25 095
SE	8.56	9.20	+7	1.540	NR	NA	43 755	46 446
SI	5.91	8.33	+41	0.360	0.462	+28	28 805	31 022
SK	5.33	6.33	+19	0.515	0.410	-20	25 835	29 046
TR	1.55	3.21	+107	0.291	1.550	+433	18 270	19 654
UA	0.56	NR	NA	0.109	NR	NA	8282	8 684
UK	7.49	7.89	+5	1.309	1.330	+2	36 456	40 745

**FIGURE 1** Changes in FVIII IU/Capita use 2008-2014

cent increase, as well as a general increase in FVIII consumption over GDP. Hungary now reports the highest per capita use of FVIII. This may be partly due to a greater prevalence of people with severe FVIII

deficiency in Hungary per million population compared to many western European countries as Hungary did not import factor concentrates in the 1980s, and thus, their haemophilia population were not

exposed to infection with, or mortality from, HIV. In the next survey, we will look to assess the average use per patient per year with severe FVIII deficiency in addition to per capita use. However, some western European countries have seen reductions (Portugal) and/or lack of significant increase (Greece, Poland and the UK) in their FVIII per capita consumption.

The 2015 survey results for FIX per capita consumption show a mean of 0.5 IU per capita in the 25 countries that reported these data, a small (1.6 per cent in the UK) to sometimes very significant increase (1344 per cent in Albania) in FIX use per capita over the last 3 years in two-thirds of respondents but a decrease of between six per cent (in Azerbaijan) and 44 per cent (in Romania) in the remaining one-third of respondents and little improvement of FIX consumption over GDP.

Survey results also show a general trend towards modest improvements in care in some areas. Six more countries have CCCs compared to in 2012. Four more countries have increased access to home treatment. Children and adults both have increased access to prophylaxis with a significant increase in access in prophylaxis availability in adults in 13 countries. There is a general improvement in access to comprehensive care services. However, this is contrasted by some setbacks or no change in other areas. One country, Ukraine, has lost access to home treatment since 2012. There are no changes in NHCs. Access to psychosocial care remains poor. There has been no real increase in access to ITI. In addition, data from the newly surveyed area of ageing reveal that most countries are poorly prepared for an ageing haemophilia population, do not have guidelines regarding ageing and PWH and/or are unaware of ageing-related services, whereas a majority of patients or centres have raised concerns about the provision of care for this segment of their population. There results also reported clear disparities within Europe with regard to patient access to key services that are core to, or augment, the provision of comprehensive care.

Following the previous EHC survey⁵, the EDQM met in 2013 and agreed further recommendations on haemophilia.³ These included a recommendation that a formal body be established in each country to include the haemophilia clinicians, national haemophilia patient organization, health ministry and paying authority. At that time, 19 countries had established such bodies - usually National Haemophilia Councils or informal bodies. In this survey, this had decreased to 18 countries. This is a matter of concern as these bodies are ideal vehicles for coordination of haemophilia care. A further recommendation was that the minimum FVIII use per capita in any country should be 3 IU per capita. In 2013, 13 countries reported per capita FVIII use below

3 IU per capita. In this survey, eight countries reported per capita use below this figure but no data are available for ten countries. Following this survey, further EDQM recommendations were agreed in 2016, which should be published in the near future. Our future surveys will track the progress in implementing these new recommendations.

DISCLOSURES

The authors stated that they have no interests that might be perceived as posing a conflict or a bias.

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SUPPORTING INFORMATION

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