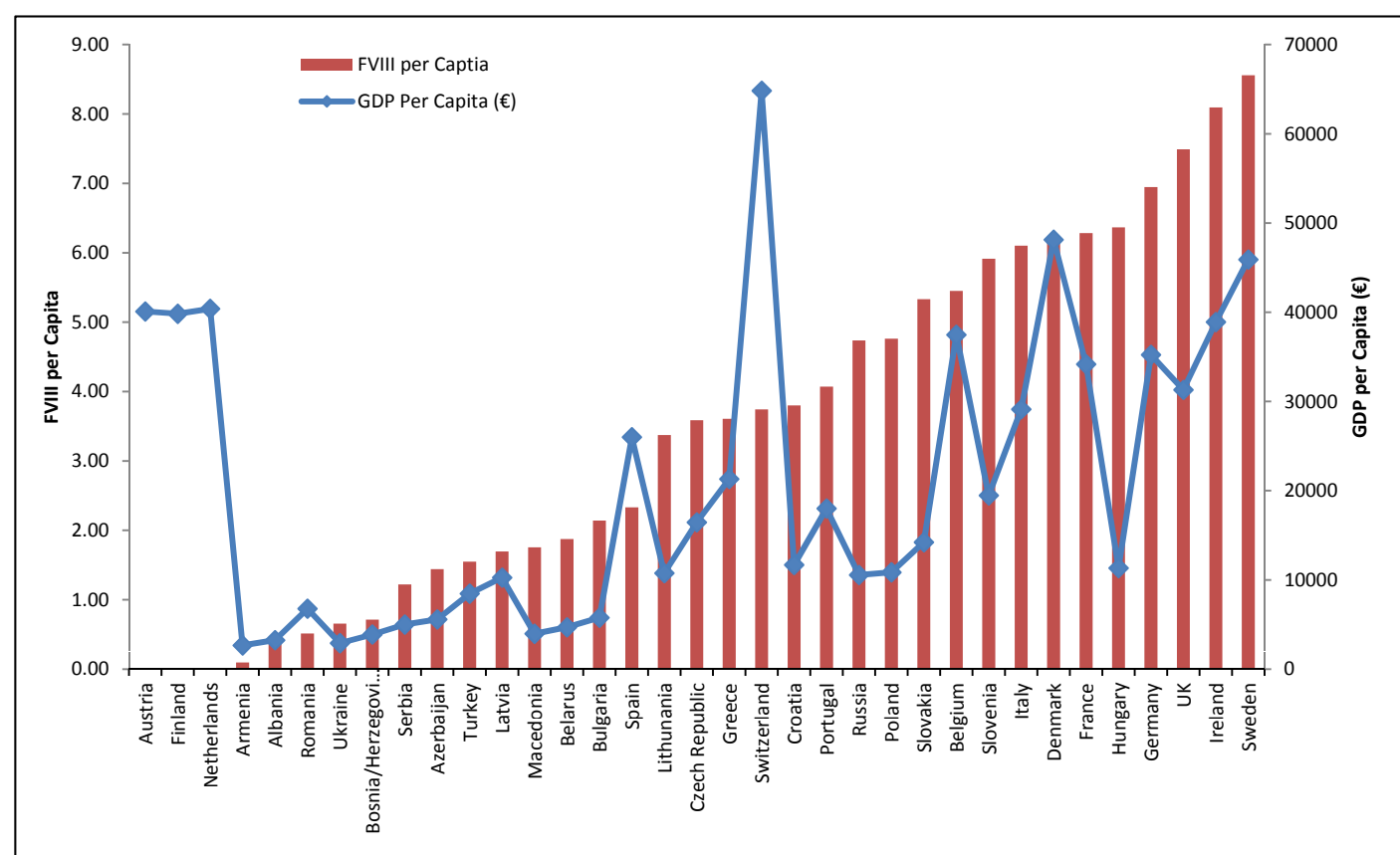


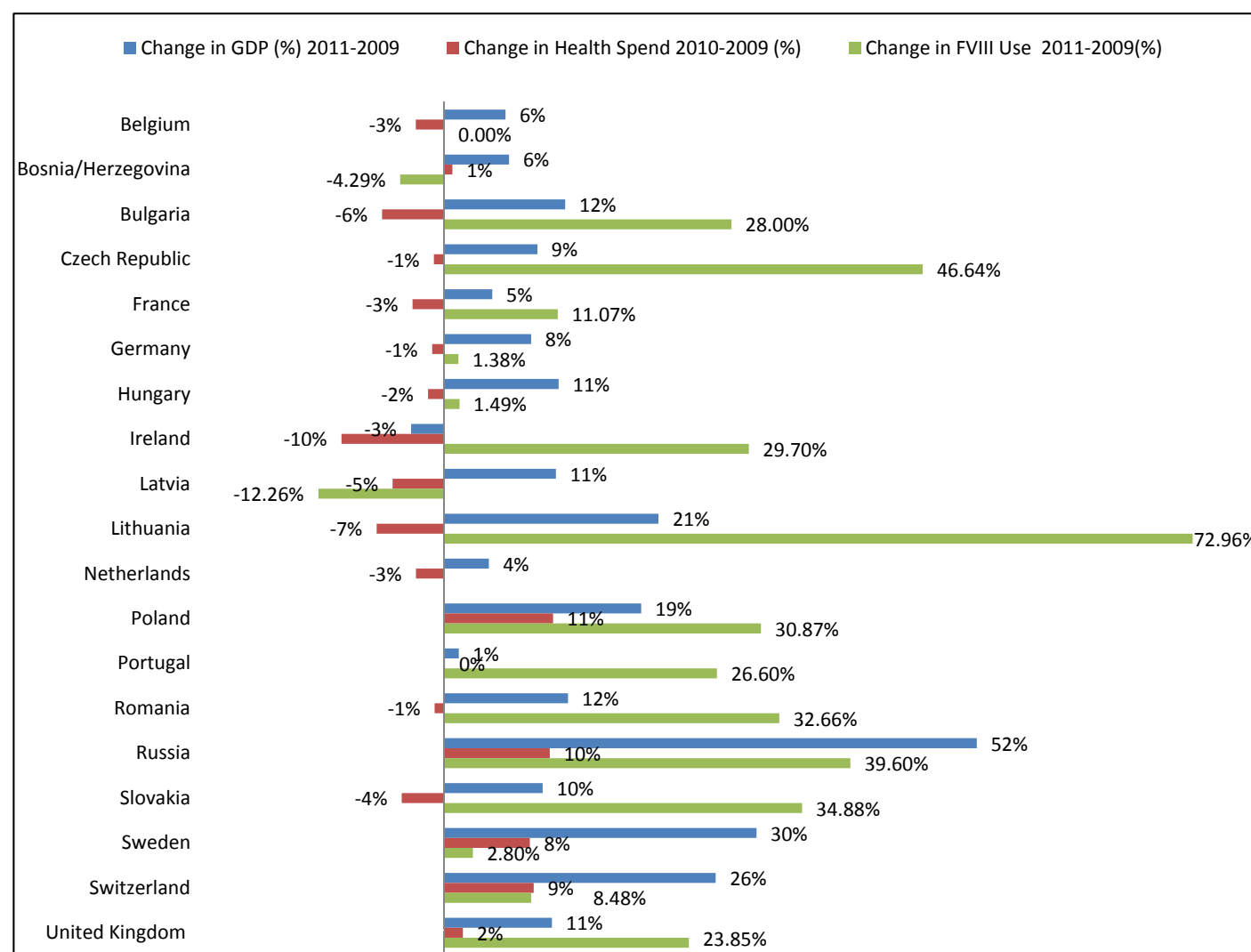


# Haemophilia Care in Europe 2012

Country	Albania	Armenia	Austria	Azerbaijan	Belarus	Belgium	Bosnia/Herzegovina	Bulgaria	Croatia	Czech Republic	Denmark	Finland	France	Germany	Greece	Hungary	Ireland	Italy	Latvia	Lithuania	Macedonia	Netherlands	Poland	Portugal	Romania	Russia	Serbia	Slovakia	Slovenia	Spain	Sweden	Switzerland	Turkey	UK	Ukraine	
FVIII per Capita	0.40	0.10	Unknown	1.44	1.87	5.45	0.71	2.14	3.80	3.59	6.17	Unknown	6.28	6.95	3.61	6.37	8.09	6.10	1.70	3.37	1.76	Unknown	4.76	4.07	0.51	4.74	1.22	5.33	5.91	2.33	8.56	3.74	1.55	7.49	0.66	
FIX per Capita	0.016	0.000	Unknown	0.218	0.204	Unknown	0.160	0.134	Unknown	Unknown	1.247	Unknown	1.039	1.017	0.599	0.495	2.661	0.825	0.216	0.615	0.462	Unknown	0.528	0.633	0.187	0.493	0.101	0.515	0.360	Unknown	1.54	0.688	0.291	1.309	0.109	
Comprehensive Care Centres (CCC's)	No	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	No	No	No	Yes	Yes	No	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	
Haemophilia Treatment Centres	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
National Haemophilia Council or Co-ordinating group	Yes	Yes	No	No	No	Yes	No	No	No	Yes	No	Yes	Yes	Yes	Yes	No	Yes	Yes	No	Yes	No	Yes	Yes	No	No	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	No	
Organisation of Patient Care																																				
Number of groups in Decision Making on Haemophilia Care	2	3	2	3	1	3	1	2	2	2	2	3	3	3	3	1	3	3	2	2	Unknown	3	3	3	1	3	3	3	2	2	1	2	3	3	2	
Number of groups choosing Haemophilia treatment products	2	2	1	2	1	1	2	1	2	1	Unknown	1	3	2	1	3	3	3	1	1	Unknown	3	1	3	1	2	3	3	2	2	1	1	3	3	2	
National Tender for procurement of Factor Concentrates	Yes	Yes	No	Yes	Yes	No	No	No	No	No	No	Yes	No	No	Yes	Yes	Yes	No	Yes	Yes	Yes	No	Yes	No	No	Yes	Yes	Yes	No	No	No	No	No	Yes	Yes	
Home Treatment	No	No	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	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Percentage of people with haemophilia use home treatment	None	None	76-100%	less than 10%	10-50%	76-100%	less than 10%	10-50%	10-50%	76-100%	51-75%	76-100%	76-100%	76-100%	76-100%	51-75%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	51-75%	None	51-75%	10-50%	76-100%	10-50%	76-100%	76-100%	76-100%	51-75%	76-100%	less than 10%	
Treatment delivered to the patient's home	No	No	Yes	No	Unknown	No	No	No	No	No	Some	No	No	No	Yes	No	Yes	Some	No	Yes	No	Some	Some	No	No	No	No	No	Some	Some	Some	Yes	No	Yes	Some	
Prophylaxis Treatment availability	Yes for Some	No	Yes to All	Yes for Some	Yes for Some	Yes to All	Yes for Some	Yes for Some	Yes to All	Yes to All	Yes for Some	Yes to All	Yes to All	Yes to All	Yes to Children	Yes to All	Yes to All	Yes to All	Yes for Some	Yes to Children	Yes to Children	Yes to All	Yes to Children	Yes for Some	Yes for Some	Yes for Some	Yes for Some	Yes to All	Yes to All	Yes to All	Yes to All	Yes to All	Yes to All	Yes to All	Yes for Some	
Children currently on Prophylaxis	None	None	51-75%	1-25%	1-25%	76-100%	1-25%	51-75%	1-25%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	51-75%	1-25%	76-100%	76-100%	76-100%	76-100%	51-75%	None	51-75%	1-25%	76-100%	26-50%	76-100%	76-100%	76-100%	51-75%	76-100%	1-25%	
Adults currently on Prophylaxis	None	None	1-25%	1-25%	1-25%	51-75%	None	1-25%	1-25%	26-50%	51-75%	26-50%	26-50%	26-50%	26-50%	26-50%	26-50%	26-50%	26-50%	26-50%	26-50%	26-50%	26-50%	26-50%	None	26-50%	1-25%	26-50%	1-25%	76-100%	1-25%	76-100%	1-25%	76-100%	1-25%	
Access to ITT	None	None	76-100%	None	1-25%	76-100%	None	None	1-25%	Unknown	76-100%	76-100%	26-50%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	1-25%	None	76-100%	76-100%	26-50%	None	26-50%	None	76-100%	76-100%	76-100%	76-100%	76-100%	1-25%	76-100%	1-25%
Emergency medicine and acute surgery	Sometimes	Unknown	Yes	Yes	Yes	Yes	Unknown	Yes	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unknown	Yes	Yes	Sometimes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Sometimes	
Paediatrics	Sometimes	Yes	Yes	Yes	Yes	Yes	Unknown	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	Never	Unknown	Yes	Never	Yes	Yes	Unknown	Yes	Sometimes	Yes	Sometimes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Sometimes	Yes	Unknown	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Hepatology	Sometimes	Unknown	Yes	Sometimes	Yes	Yes	Unknown	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	
Rheumatology	Never	Unknown	Yes	Yes	Yes	Yes	Unknown	Sometimes	Sometimes	Sometimes	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	
Orthopaedics	Sometimes	Yes	Yes	Yes	Yes	Yes	Unknown	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	
Physiotherapy	Sometimes	Yes	Yes	Yes	Yes	Yes	Unknown	Sometimes	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	
Dentistry	Sometimes	Yes	Yes	Yes	Yes	Yes	Unknown	Sometimes	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	
Obstetrics and gynaecology	Never	Unknown	Yes	Yes	Yes	Yes	Unknown	Yes	Sometimes	Yes	Yes	Unknown	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Genetics	Never	Unknown	Yes	Never	Yes	Yes	Unknown	Sometimes	Yes	Yes	Yes	Unknown	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Social and psychological support	Yes	Yes	Yes	Sometimes	Never	Yes	Unknown	Sometimes	Sometimes	Yes	Sometimes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Pain management	Never	Unknown	Yes	Yes	Yes	Yes	Unknown	Never	Sometimes	Sometimes	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	
General surgery	Sometimes	Unknown	Yes	Yes	Yes	Yes	Unknown	Never	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	
Urology	Sometimes	Unknown	Yes	Yes	Yes	Yes	Unknown	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	
Number with Haemophilia A	227	220	546	1065	439	941	72	550	412	600	388	Unknown	4709	4000	752	539	3481	118	150	210	Unknown	2216	531	1414	4720	400	491	182	1679	857	585	3850	6491	2000		
Number with Haemophilia B	56	50	99	98	95	212	20	68	89	300	93	Unknown	1031	700	147	207	200	717	25	20	105	Unknown	389	110	194	701	69	72	21	277	198	116	719	1482	300	
Number with von Willebrand Disease	2	8	36	200	176	1467	22	90	245	Unknown	391	Unknown	1338	4500	792	1318	817	1958	102	300	Unknown	1199	48	348	1254	210	551	154	709	1808	136	Unknown	9184	400		
Haemophilia Replacement Therapy																																				
Plasma	Rarely	Always	Never	Rarely	Rarely	Never	Unknown	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Rarely	Never	Never	Never	Never	Never	Never	Never	Rarely	
Cryoprecipitate	Always	Always	Never	Unknown	Rarely	Never	Unknown	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Rarely	Never	Never	Never	Never	Never	Never	Never	Rarely	
Plasma-derived Factor Conc.	Never	Rarely	Always	Always	Always	Rarely	Always	Always	Always	Always	Always	Always	Rarely	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Rarely	
Recombinant Factor Conc.	Rarely	Rarely	Always	Always	Never	Always	Rarely	Always	Always	Rarely	Always	Always	Always	Always	Always	Always	Always	Always	Rarely	Always	Rarely	Always	Rarely	Always	Always	Rarely	Rarely	Always	Always	Always	Always	Always	Always	Always	Rarely	
von Willebrand Disease	Never	Always	Never	Rarely	Never	Never	Unknown	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Rarely	Rarely	Never	Never	Never	Never	Never	Never	Never	Rarely	
Cryoprecipitate	Never	Always	Never	Unknown	Always	Never	Unknown	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Never	Rarely	Rarely	Never	Never	Never	Never	Never	Never	Never	Rarely	
Plasma-derived Factor Conc.	Never	Rarely	Always	Rarely	Rarely	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Rarely	Rarely	Rarely	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	
DDAVP	Rarely	Rarely	Always	Unknown	Rarely	Always	Unknown	Rarely	Rarely	Always	Always	Always	Always	Always	Always	Unknown	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Always	Never



Comparison of GDP per capita (€) and Factor VIII per capita use



19 Countries 2009 Survey- Changes



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# HAEMOPHILIA CARE IN EUROPE SURVEY OF 35 COUNTRIES

European Haemophilia Consortium

Brian O'Mahony



The continent of Europe is a disparate one with a wide range of economic conditions and health systems in individual countries. In 2009, a survey was carried out in order to determine the extent to which Haemophilia Care in European countries compared with the European principles of haemophilia care which were drafted by an inter-disciplinary group of haemophilia physicians with input from key patient opinion leaders and endorsed by EHC and EAHAD.

The principles outlined were:

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

A total of 19 countries responded to this survey and the results were published in 2010 in the journal *Haemophilia*. The survey revealed significant variation in relation to the organisation of haemophilia care and availability of factor concentrates in the European countries surveyed.

We repeated the survey this year (2012) and broadened the questions to elicit more specific information. A total of 35 of the 43 European countries who are members of the EHC responded. This was an excellent response and the EHC would like to sincerely thank all of the countries for responding. The latest data is presented here in tabular form. The data has also been submitted for publication to the journal *haemophilia* and a separate Monograph is also planned for distribution by the EHC.

Countries who Responded	
EU	Non-EU
Austria	Albania
Belgium	Armenia
Bulgaria	Azerbaijan
Czech Republic	Belarus
Denmark	Bosnia-Herzegovina
France	Croatia
Finland	Macedonia
Germany	Russia
Greece	Serbia
Hungary	Switzerland
Ireland	Turkey
Italy	Ukraine
Lithuania	
Latvia	
Netherlands	
Poland	
Portugal	
Romania	
Slovak Republic	
Slovenia	
Spain	
Sweden	
United Kingdom	