

Modell's

Haemoglobinopathologist's

Almanac

Epidemiological Estimates for Haemoglobin Disorders: WHO European Region by Country

Comprising the following charts and tables:

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Charts and tables compiled showing conservative estimates based on best available data presented on the World Wide Web in May 2007 by Professor Bernadette Modell (b.modell@pcps.ucl.ac.uk) and Matthew Darlison (m.darlison@ucl.ac.uk), UCL Centre for Health Informatics and Multiprofessional Education (CHIME) and World Health Organisation Collaborating Centre for the Community Control of Hereditary Disorders.

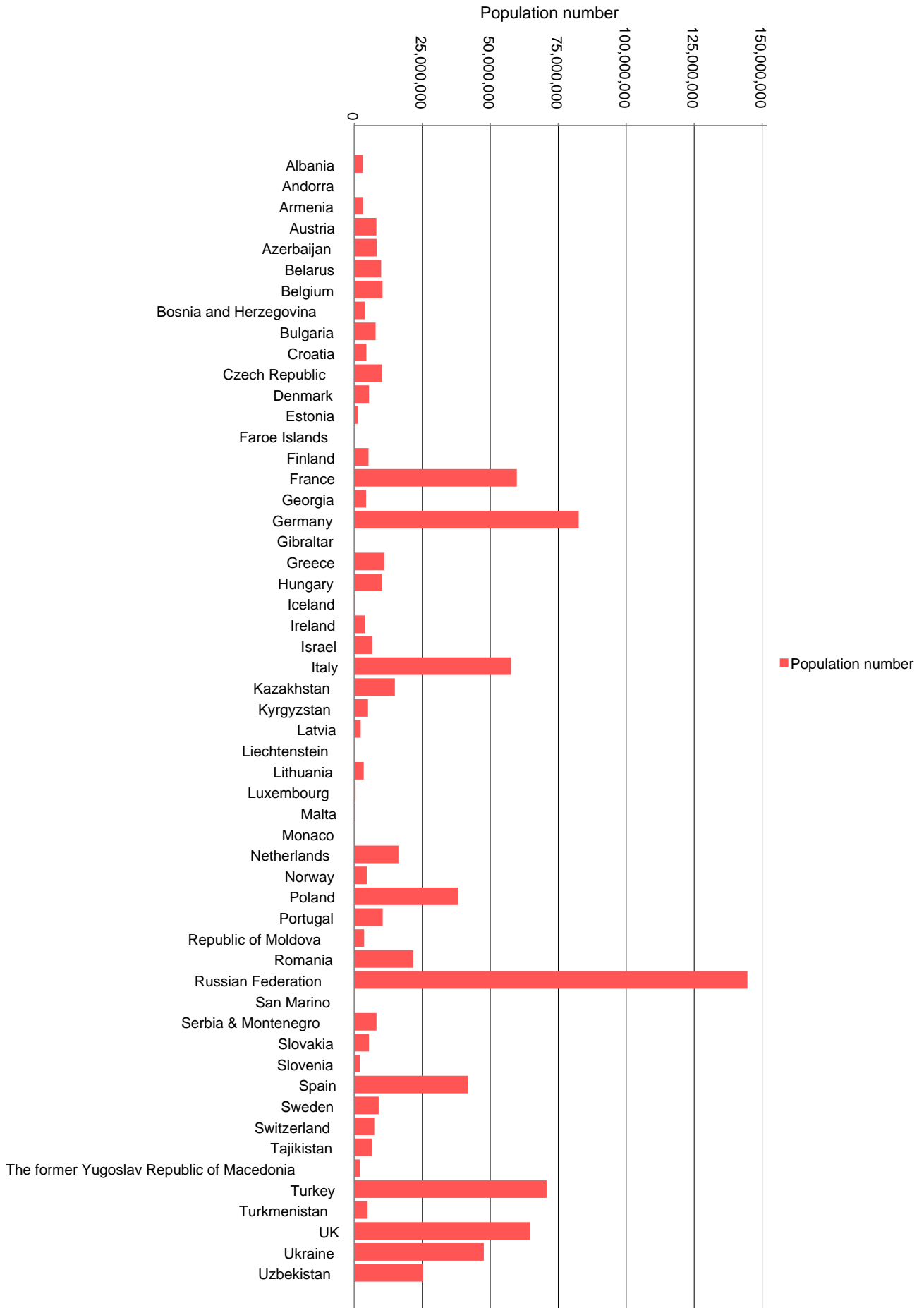
Definitions used

In terms of alpha globin genotypes, we define as pathological homozygous alpha zero thalassaemia (causes hydrops fetalis) and the combination of alpha zero and alpha plus thalassaemia (causes haemoglobin H disease). Homozygous alpha plus thalassaemia is not considered to cause pathology. In terms of beta globin genotypes, we define as pathological haemoglobin S/C, homozygous haemoglobin S (SS), haemoglobin S/beta thalassaemia, homozygous beta thalassaemia, haemoglobin E/beta thalassaemia and some rare combinations. We define as harmless homozygous haemoglobin C (CC), haemoglobin C/beta thalassaemia, homozygous haemoglobin E (EE), homozygous haemoglobin D (DD), haemoglobin D/beta thalassaemia, and some other rare combinations.

WHO Regions are constituted as follows:

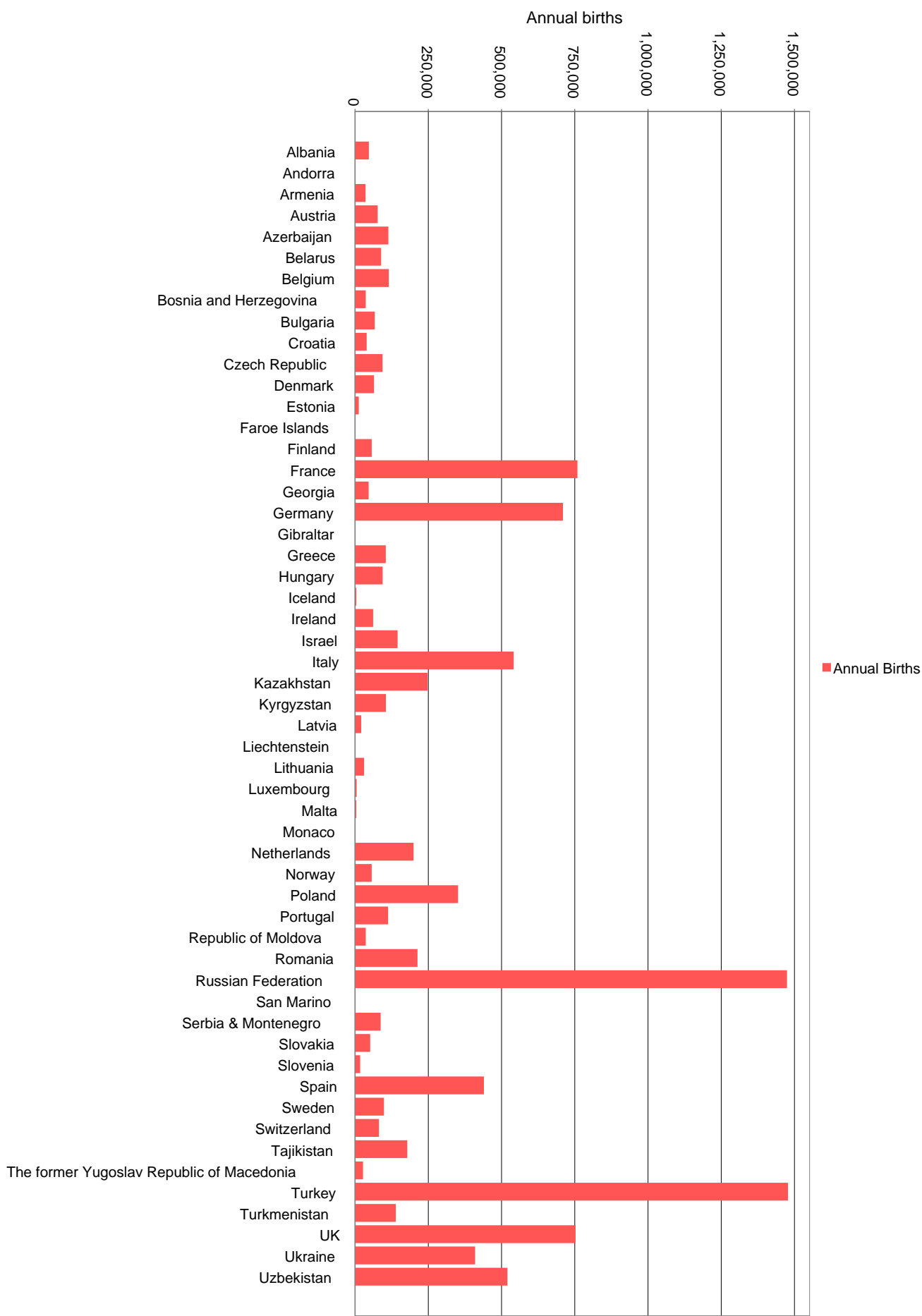
African Region (AFR)	American Region (AMR)	Eastern Mediterranean Region (EMR)	European Region (EUR)	South East Asian Region (SEAR)	Western Pacific Region (WPR)
<p>Northern Africa: Algeria</p> <p>Western Africa: Benin, Burkina Faso, Cote d'Ivoire, Cape Verde, Gambia, Guinea-Bissau, Ghana, Guinea, Liberia, Mali, Mauritania, Niger, Nigeria, Sierra Leone, Saint Helena, Senegal, Togo</p> <p>Middle Africa: Angola, Central African Republic, Cameroon, Chad, Congo, Democratic Republic of the Congo (formerly Zaire), Equatorial Guinea, Gabon, Sao Tome and Principe</p> <p>Eastern Africa: Burundi, Comoros, Kenya, Madagascar, Malawi, Mauritius, Mayotte, Mozambique, Reunion, Rwanda, Seychelles, United Republic of Tanzania, Uganda, Zambia, Zimbabwe</p> <p>Southern Africa: Botswana, Lesotho, Namibia, South Africa, Swaziland</p>	<p>Northern America: Bermuda, Canada, Greenland, Saint Pierre and Miquelon, United States</p> <p>Central America: Belize, Costa Rica, El Salvador, Guatemala, Honduras, Mexico, Nicaragua, Panama</p> <p>Caribbean: Anguilla, Antigua and Barbuda, Aruba, Bahamas, Barbados, British Virgin Islands, Cayman Islands, Cuba, Dominica, Dominican Republic, Grenada, Guadeloupe, Haiti, Jamaica, Martinique, Montserrat, Netherlands Antilles, Puerto Rico, Saint Kitt's and Nevis, Saint Vincent and the Grenadines, Saint Lucia, Trinidad and Tobago, Turks and Caicos Islands, US Virgin Islands</p> <p>South America: Argentina, Bolivia, Brazil, Chile, Colombia, Ecuador, Falkland Islands, French Guiana, Guyana, Paraguay, Peru, Suriname, Uruguay, Venezuela</p>	<p>Northern Africa: Libyan Arab Jamahiriya, Morocco, Sudan, Tunisia, Western Sahara</p> <p>Eastern Africa: Djibouti, Egypt, Eritrea, Ethiopia, Somalia</p> <p>Western Asia: Bahrain, Cyprus, Iraq, Jordan, Kuwait, Lebanon, Oman, Qatar, Saudi Arabia, Syrian Arab Republic, United Arab Emirates, Yemen</p> <p>South Central Asia: Afghanistan, Iran, Islamic Republic of, Pakistan, Occupied Palestinian territory</p>	<p>Northern Europe: Channel Islands, Denmark, Estonia, Faroe Islands, Finland, Isle of Man, Iceland, Ireland, Latvia, Lithuania, Norway, Sweden, United Kingdom</p> <p>Western Europe: Austria, Belgium, France, Germany, Liechtenstein, Luxembourg, Monaco, Netherlands, Switzerland</p> <p>Southern Europe: Albania, Andorra, Bosnia and Herzegovina, Croatia, Gibraltar, Greece, Italy, The former Yugoslav Republic of Macedonia, Malta, Portugal, San Marino, Slovenia, Spain, Yugoslavia</p> <p>Eastern Europe: Belarus, Bulgaria, Czech Republic, Hungary, Republic of Moldova, Poland, Romania, Russian Federation, Slovakia, Ukraine</p> <p>South Central Asia: Kazakhstan, Kyrgyzstan, Tajikistan, Turkmenistan, Uzbekistan</p> <p>Western Asia: Armenia, Azerbaijan, Georgia, Israel, Turkey</p>	<p>South Central Asia: Bangladesh, Bhutan, India, Maldives, Nepal, Sri Lanka</p> <p>South Eastern Asia: East Timor, Indonesia, Myanmar, Thailand</p>	<p>Eastern Asia: China, China - Hong Kong, Japan, Korea, Democratic Peoples' Republic of Korea, Republic of, China - Macau, Mongolia, Taiwan, Province of China</p> <p>South Eastern Asia: Brunei Darussalam, Cambodia, Heard Island and McDonald Islands, Lao Peoples' Democratic Republic, Malaysia, Philippines, Singapore, Vietnam</p> <p>Melanesia, Micronesia, Polynesia: American Samoa, Cook Islands, Fiji, French Polynesia, Guam, Kiribati, Marshall Islands, Micronesia, Federated States of New Caledonia, Northern Mariana Islands, Nauru, Niue, Palau, Pitcairn, Papua New Guinea, Samoa, Solomon Islands, Tokelau, Tonga, Tuvalu, Vanuatu, Wallis and Futuna Islands</p> <p>Australia and New Zealand: Australia, New Zealand</p>

Chart 1: Population



<i>Country</i>	<i>Population number</i>
Albania	3,111,000
Andorra	70,000
Armenia	3,211,000
Austria	8,118,000
Azerbaijan	8,234,000
Belarus	9,874,000
Belgium	10,376,000
Bosnia and Herzegovina	3,832,000
Bulgaria	7,824,000
Croatia	4,442,000
Czech Republic	10,202,000
Denmark	5,387,000
Estonia	1,354,000
Faroe Islands	48,000
Finland	5,213,000
France	59,768,000
Georgia	4,329,000
Germany	82,534,000
Gibraltar	29,000
Greece	11,024,000
Hungary	10,130,000
Iceland	289,000
Ireland	3,996,000
Israel	6,690,000
Italy	57,605,000
Kazakhstan	14,909,000
Kyrgyzstan	5,039,000
Latvia	2,325,000
Liechtenstein	34,000
Lithuania	3,454,000
Luxembourg	450,000
Malta	399,000
Monaco	32,000
Netherlands	16,225,000
Norway	4,565,000
Poland	38,195,000
Portugal	10,441,000
Republic of Moldova	3,613,000
Romania	21,734,000
Russian Federation	144,566,000
San Marino	29,000
Serbia & Montenegro	8,153,000
Slovakia	5,379,000
Slovenia	1,997,000
Spain	41,874,000
Sweden	8,958,000
Switzerland	7,341,000
Tajikistan	6,573,000
The former Yugoslav Republic of Macedonia	2,027,000
Turkey	70,713,000
Turkmenistan	4,859,000
UK	64,616,011
Ukraine	47,633,000
Uzbekistan	25,368,000
WHO European Region population total	879,191,011

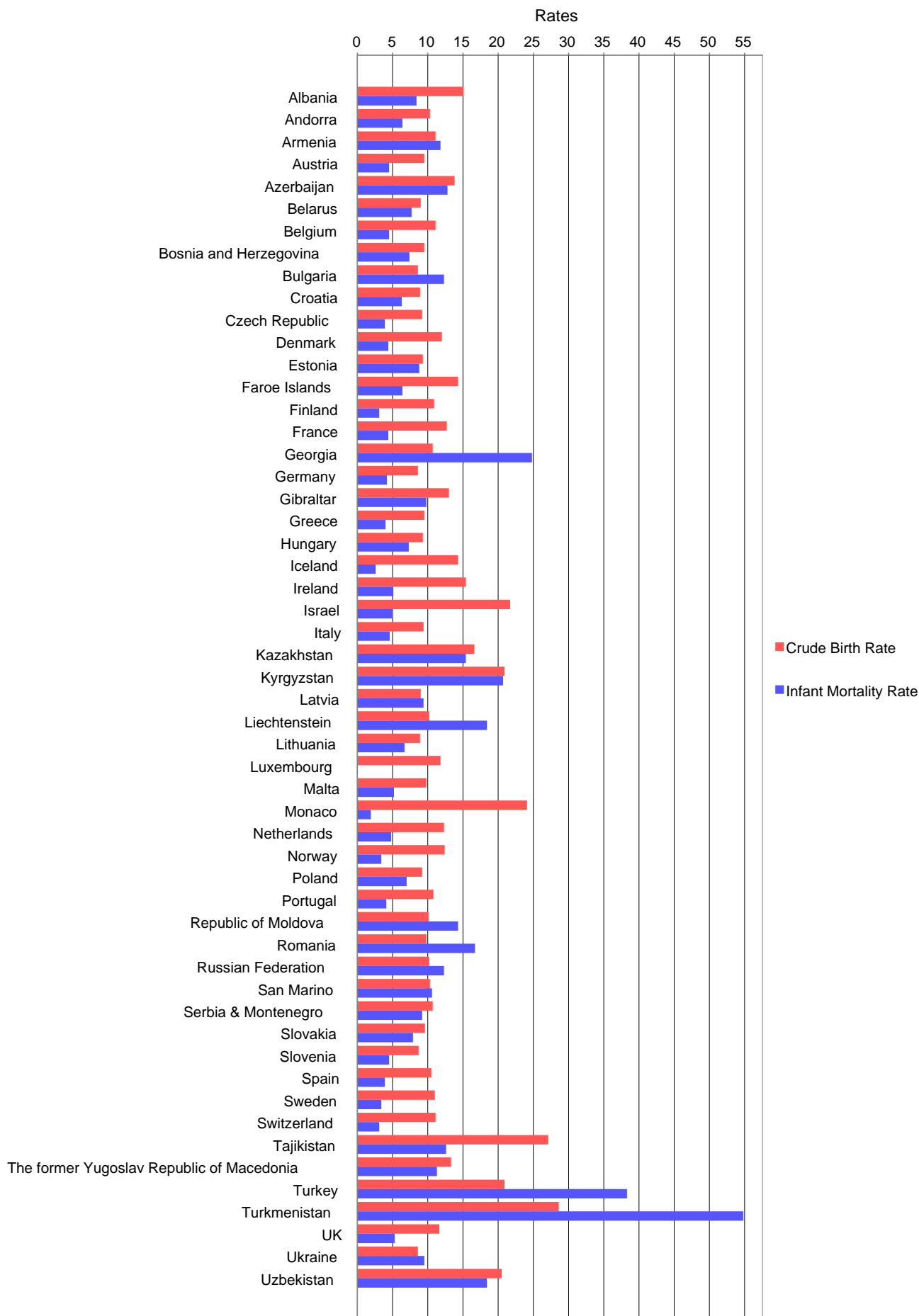
Chart 2: Annual births



Indicates requirement for carrier screening during pregnancy. The annual number of people marrying (not shown) is the indicator for pre-marital or pre-pregnancy screening.

<i>Country</i>	<i>Annual Births</i>
Albania	46,976
Andorra	721
Armenia	35,642
Austria	77,121
Azerbaijan	113,629
Belarus	88,866
Belgium	115,173
Bosnia and Herzegovina	36,404
Bulgaria	67,286
Croatia	39,533
Czech Republic	93,858
Denmark	64,643
Estonia	12,592
Faroe Islands	686
Finland	56,821
France	759,053
Georgia	46,320
Germany	709,792
Gibraltar	377
Greece	104,728
Hungary	94,209
Iceland	4,132
Ireland	61,538
Israel	145,173
Italy	541,487
Kazakhstan	247,489
Kyrgyzstan	105,315
Latvia	20,925
Liechtenstein	346
Lithuania	30,740
Luxembourg	5,310
Malta	3,910
Monaco	771
Netherlands	199,567
Norway	56,606
Poland	351,393
Portugal	112,762
Republic of Moldova	36,491
Romania	212,993
Russian Federation	1,474,573
San Marino	298
Serbia & Montenegro	87,237
Slovakia	51,638
Slovenia	17,373
Spain	439,677
Sweden	98,538
Switzerland	81,485
Tajikistan	178,128
The former Yugoslav Republic of Macedonia	26,959
Turkey	1,477,901
Turkmenistan	138,967
UK	752,514
Ukraine	409,643
Uzbekistan	520,044
WHO European Region total births	10,456,353

Chart 3: Crude birth rate and infant mortality rate



Crude birth rate (CBR) = live births per 1000 population per year; infant mortality rate (IMR) = deaths under 1 year, per 1,000 live births.

<i>Country</i>	<i>Crude Birth Rate</i>	<i>Infant Mortality Rate</i>
Albania	15.1	8.4
Andorra	10.3	6.4
Armenia	11.1	11.8
Austria	9.5	4.5
Azerbaijan	13.8	12.8
Belarus	9	7.7
Belgium	11.1	4.5
Bosnia and Herzegovina	9.5	7.4
Bulgaria	8.6	12.3
Croatia	8.9	6.3
Czech Republic	9.2	3.9
Denmark	12	4.4
Estonia	9.3	8.8
Faroe Islands	14.3	6.4
Finland	10.9	3.1
France	12.7	4.4
Georgia	10.7	24.8
Germany	8.6	4.2
Gibraltar	13	9.8
Greece	9.5	4
Hungary	9.3	7.3
Iceland	14.3	2.6
Ireland	15.4	5.1
Israel	21.7	4.9
Italy	9.4	4.6
Kazakhstan	16.6	15.4
Kyrgyzstan	20.9	20.7
Latvia	9	9.4
Liechtenstein	10.2	18.4
Lithuania	8.9	6.7
Luxembourg	11.8	0
Malta	9.8	5.2
Monaco	24.1	1.9
Netherlands	12.3	4.8
Norway	12.4	3.4
Poland	9.2	7
Portugal	10.8	4.1
Republic of Moldova	10.1	14.3
Romania	9.8	16.7
Russian Federation	10.2	12.3
San Marino	10.3	10.6
Serbia & Montenegro	10.7	9.2
Slovakia	9.6	7.9
Slovenia	8.7	4.5
Spain	10.5	3.9
Sweden	11	3.4
Switzerland	11.1	3.1
Tajikistan	27.1	12.6
The former Yugoslav Republic of Macedonia	13.3	11.3
Turkey	20.9	38.3
Turkmenistan	28.6	54.8
UK	11.646	5.3
Ukraine	8.6	9.5
Uzbekistan	20.5	18.4
WHO European Region aggregate rates	11	13

Chart 4: Per cent of pregnant women carrying alpha globin gene variants, by variant

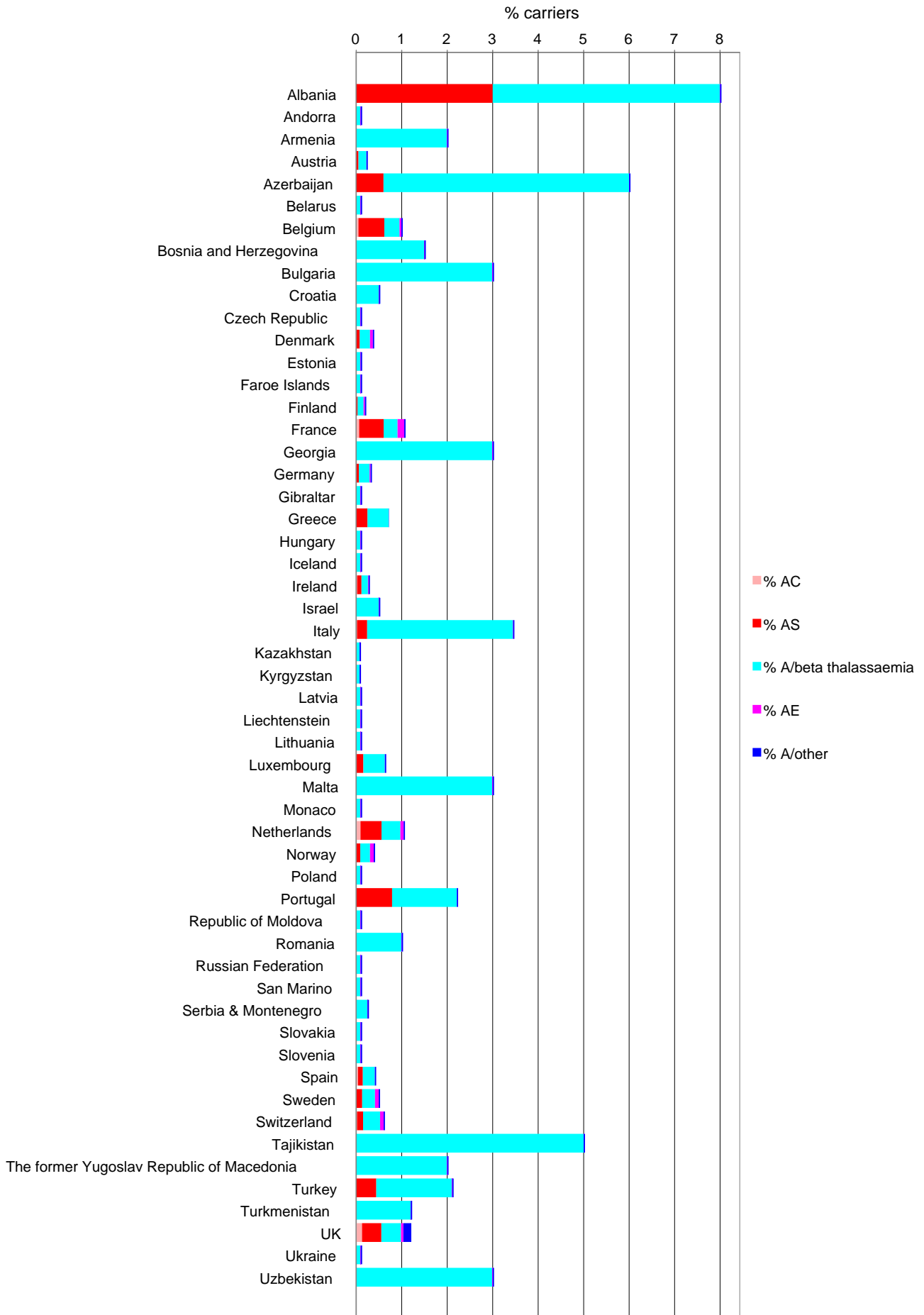


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Data is for deletional alpha globin gene variants. Homozygous alpha plus thalassaemia is included as it is common and harmless.

Country	% alpha zero thalassaemia carrier	% alpha plus thalassaemia carrier	% homozygous alpha plus thalassaemia
Albania	0	8.587	0.206
Andorra	0	0	0
Armenia	0	1.98	0.01
Austria	0.006	0.241	0.039
Azerbaijan	0	28.454	3.173
Belarus	0	0	0
Belgium	0.018	2.239	0.537
Bosnia and Herzegovina	0	1.978	0.011
Bulgaria	0	0	0
Croatia	0	1.978	0.011
Czech Republic	0	0	0
Denmark	0.023	0.647	0.075
Estonia	0	0	0
Faroe Islands	0	0	0
Finland	0.012	0.215	0.028
France	0.021	2.511	0.585
Georgia	0	1.98	0.01
Germany	0.01	0.364	0.039
Gibraltar	0	0	0
Greece	0.004	0.905	0.049
Hungary	0	0	0
Iceland	0	0	0
Ireland	0.017	0.399	0.717
Israel	0	5.82	0.09
Italy	0.007	0.498	0.064
Kazakhstan	0	6.748	0.126
Kyrgyzstan	0	6.57	0.215
Latvia	0	0	0
Liechtenstein	0	0	0
Lithuania	0	0	0
Luxembourg	0.018	0.471	1.148
Malta	0	0	0
Monaco	0	0	0
Netherlands	0.007	1.893	2.972
Norway	0.026	0.746	1.186
Poland	0	0	0
Portugal	0.003	0.762	0.107
Republic of Moldova	0	0	0
Romania	0	9.481	0.26
Russian Federation	0	0	0
San Marino	0	0	0
Serbia & Montenegro	0	1.978	0.011
Slovakia	0	0	0
Slovenia	0	0	0
Spain	0.007	0.641	0.075
Sweden	0.03	0.874	1.429
Switzerland	0.032	0.955	1.618
Tajikistan	0	12.655	0.672
The former Yugoslav Republic of Macedonia	0	11.621	0.39
Turkey	0	2.927	0.037
Turkmenistan	0	12.99	0.505
UK	0.07	1.778	0
Ukraine	0	0	0
Uzbekistan	0	13.006	0.497
WHO European Region aggregate carrier rates	0.009	2.868	0.25

Chart 5: Per cent of pregnant women carrying beta globin gene variants, by variant



Country	% AC	% AS	% A/beta thalassaemia	% AE	% A/other
Albania	0	3	5	0	0.03
Andorra	0	0	0.1	0	0.03
Armenia	0	0	2	0	0.03
Austria	0.004	0.045	0.173	0.001	0.03
Azerbaijan	0	0.6	5.4	0	0.03
Belarus	0	0	0.1	0	0.03
Belgium	0.049	0.569	0.335	0.039	0.03
Bosnia and Herzegovina	0	0	1.5	0	0.03
Bulgaria	0	0	3	0	0.03
Croatia	0	0	0.5	0	0.03
Czech Republic	0	0	0.1	0	0.03
Denmark	0.009	0.069	0.225	0.063	0.03
Estonia	0	0	0.1	0	0.03
Faroe Islands	0	0	0.1	0	0.03
Finland	0.004	0.026	0.132	0.029	0.03
France	0.064	0.54	0.306	0.145	0.03
Georgia	0	0	3	0	0.03
Germany	0.008	0.05	0.235	0.022	0.03
Gibraltar	0	0	0.1	0	0.03
Greece	0.002	0.246	0.468	0.004	0.003
Hungary	0	0	0.1	0	0.03
Iceland	0	0	0.1	0	0.03
Ireland	0.02	0.096	0.141	0.014	0.03
Israel	0	0	0.5	0	0.03
Italy	0.018	0.223	3.2	0.007	0.03
Kazakhstan	0	0	0.075	0	0.03
Kyrgyzstan	0	0	0.075	0	0.03
Latvia	0	0	0.1	0	0.03
Liechtenstein	0	0	0.1	0	0.03
Lithuania	0	0	0.1	0	0.03
Luxembourg	0.012	0.145	0.472	0.001	0.03
Malta	0	0	3	0	0.03
Monaco	0	0	0.1	0	0.03
Netherlands	0.093	0.463	0.414	0.072	0.03
Norway	0.008	0.08	0.215	0.081	0.03
Poland	0	0	0.1	0	0.03
Portugal	0.007	0.782	1.42	0.002	0.029
Republic of Moldova	0	0	0.1	0	0.03
Romania	0	0	1	0	0.03
Russian Federation	0	0	0.1	0	0.03
San Marino	0	0	0.1	0	0.03
Serbia & Montenegro	0	0	0.25	0	0.03
Slovakia	0	0	0.1	0	0.03
Slovenia	0	0	0.1	0	0.03
Spain	0.037	0.108	0.262	0.002	0.029
Sweden	0.011	0.12	0.282	0.082	0.03
Switzerland	0.018	0.133	0.372	0.078	0.03
Tajikistan	0	0	5	0	0.03
The former Yugoslav Republic of Macedonia	0	0	2	0	0.03
Turkey	0.001	0.44	1.67	0	0.03
Turkmenistan	0	0	1.2	0	0.03
UK	0.128	0.425	0.431	0.054	0.173
Ukraine	0	0	0.1	0	0.03
Uzbekistan	0	0	3	0	0.03
WHO European Region aggregate carrier rates	0.02	0.202	0.967	0.021	0.04

Chart 6: Per cent of pregnant women carrying any haemoglobin gene variant



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Alpha and beta globin gene variants are inherited independently and do not interact to cause disease: many people carry both alpha and beta variants.

<i>Country</i>	<i>% carriers of alpha globin gene variants alone</i>	<i>% carriers of both alpha and beta globin gene variants</i>	<i>% carriers of beta globin gene variants alone</i>	<i>Total % carriers</i>
Albania	8.088	1.412	7.324	16.824
Andorra	0	0	0.13	0.13
Armenia	1.95	0.081	1.99	4.02
Austria	0.285	0.001	0.254	0.54
Azerbaijan	29.72	3.814	4.123	37.657
Belarus	0	0	0.13	0.13
Belgium	2.765	0.057	0.994	3.816
Bosnia and Herzegovina	1.959	0.061	1.5	3.519
Bulgaria	0	0	3.03	3.03
Croatia	1.979	0.021	0.519	2.519
Czech Republic	0	0	0.13	0.13
Denmark	0	0	0.395	0.395
Estonia	0	0	0.13	0.13
Faroe Islands	0	0	0.13	0.13
Finland	0.254	0.001	0.22	0.476
France	3.083	0.067	1.051	4.201
Georgia	1.93	0.121	2.97	5.02
Germany	0.411	0.003	0.344	0.758
Gibraltar	0	0	0.13	0.13
Greece	0.951	0.014	0.717	1.682
Hungary	0	0	0.13	0.13
Iceland	0	0	0.13	0.13
Ireland	1.13	0.007	0.297	1.434
Israel	5.879	0.063	0.499	6.44
Italy	0.549	0.039	3.458	4.047
Kazakhstan	6.867	0.014	0.098	6.979
Kyrgyzstan	6.778	0.014	0.098	6.89
Latvia	0	0	0.13	0.13
Liechtenstein	0	0	0.13	0.13
Lithuania	0	0	0.13	0.13
Luxembourg	1.625	0.021	0.649	2.295
Malta	0	0	3.03	3.03
Monaco	0	0	0.13	0.13
Netherlands	4.819	0.104	1.02	5.943
Norway	0	0	0.414	0.414
Poland	0	0	0.13	0.13
Portugal	0.853	0.039	2.22	3.113
Republic of Moldova	0	0	0.13	0.13
Romania	9.64	0.201	0.93	10.77
Russian Federation	0	0	0.13	0.13
San Marino	0	0	0.13	0.13
Serbia & Montenegro	1.984	0.011	0.274	2.269
Slovakia	0	0	0.13	0.13
Slovenia	0	0	0.13	0.13
Spain	0.72	0.006	0.436	1.162
Sweden	0	0	0.524	0.524
Switzerland	2.589	0.032	0.615	3.236
Tajikistan	12.657	1.341	4.36	18.358
The former Yugoslav Republic of Macedonia	11.767	0.488	1.786	14.04
Turkey	2.9	0.127	2.078	5.105
Turkmenistan	13.329	0.332	1.064	14.725
UK	1.826	0.045	1.188	3.059
Ukraine	0	0	0.13	0.13
Uzbekistan	13.094	0.818	2.621	16.533
WHO European Region aggregate carrier rates	3.012	0.156	1.171	4.339

Chart 7: Conceptions/1000 with combinations of significant variants

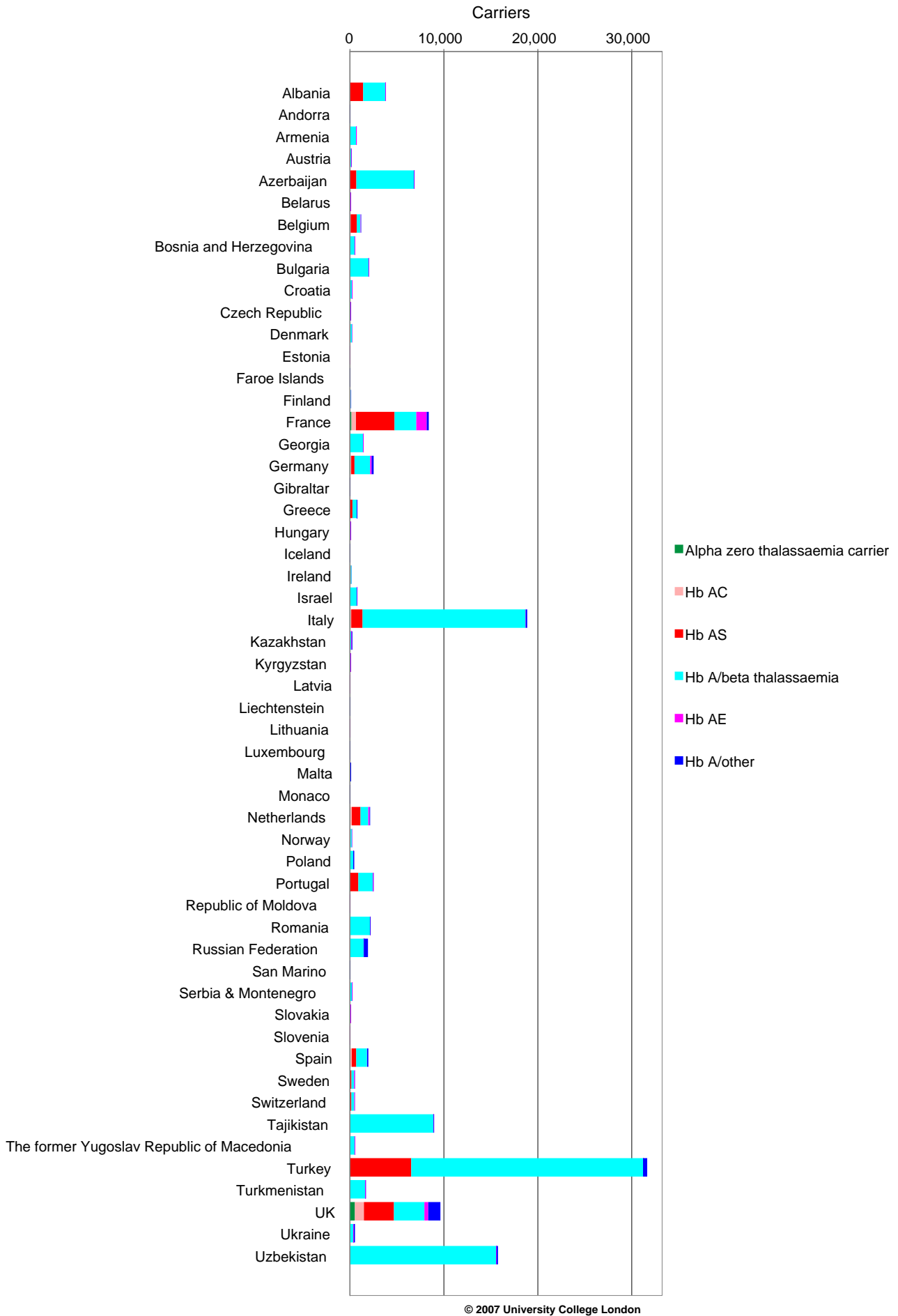


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Pathological combinations are shown individually. Harmless combinations are grouped together. For details see definitions.

Country	Hb H disease	Homozygous alpha zero thalassaemia	Hb SC	Hb SS	Hb S/beta thalassaemia	Homozygous beta thalassaemia	Hb E/beta thalassaemia	Harmless combinations	Total affected conceptions	Total conceptions
Albania	0	0	0	0.238	0.749	0.647	0	0	1.634	1.634
Andorra	0	0	0	0	0	0	0	0	0	0
Armenia	0	0	0	0	0	0.101	0	0	0.101	0.101
Austria	0	0	0	0	0.002	0.004	0	0	0.006	0.006
Azerbaijan	0	0	0	0.038	0.16	0.993	0	0	1.192	1.192
Belarus	0	0	0	0	0	0	0	0	0	0
Belgium	0	0	0.03	0.046	0.011	0.031	0	0.012	0.118	0.131
Bosnia and Herzegovina	0	0	0	0	0	0.063	0	0	0.063	0.063
Bulgaria	0	0	0	0	0	0.255	0	0	0.255	0.255
Croatia	0	0	0	0	0	0.008	0	0	0.008	0.009
Czech Republic	0	0	0	0	0	0	0	0	0	0
Denmark	0	0	0.016	0.028	0.003	0.006	0.001	0.005	0.054	0.059
Estonia	0	0	0	0	0	0	0	0	0	0
Faroe Islands	0	0	0	0	0	0	0	0	0	0
Finland	0	0	0	0	0	0	0	0	0	0.001
France	0	0	0.071	0.105	0.026	0.046	0	0.031	0.248	0.279
Georgia	0	0	0	0	0	0.226	0	0	0.226	0.226
Germany	0	0	0.014	0.032	0.006	0.019	0.007	0.021	0.079	0.099
Gibraltar	0	0	0	0	0	0	0	0	0	0
Greece	0	0	0	0.011	0.154	0.984	0	0	1.149	1.149
Hungary	0	0	0	0	0	0	0	0	0	0
Iceland	0	0	0	0	0	0	0	0	0	0
Ireland	0	0	0	0	0	0	0	0	0	0
Israel	0	0	0	0	0	0.051	0	0	0.051	0.051
Italy	0	0	0	0.005	0.041	0.351	0	0	0.397	0.397
Kazakhstan	0	0	0	0	0	0	0	0	0	0
Kyrgyzstan	0	0	0	0	0	0	0	0	0	0
Latvia	0	0	0	0	0	0	0	0	0	0
Liechtenstein	0	0	0	0	0	0	0	0	0	0
Lithuania	0	0	0	0	0	0	0	0	0	0
Luxembourg	0.017	0.002	0.009	0.059	0.009	0.055	0.001	0.002	0.152	0.154
Malta	0	0	0	0	0	0.238	0	0	0.238	0.238
Monaco	0	0	0	0	0	0	0	0	0	0
Netherlands	0	0	0.029	0.05	0.012	0.012	0.005	0.015	0.109	0.124
Norway	0	0	0.017	0.04	0.006	0.025	0.019	0.044	0.106	0.15
Poland	0	0	0	0	0	0	0	0	0	0
Portugal	0	0	0.01	0.027	0.026	0.025	0	0.002	0.088	0.09
Republic of Moldova	0	0	0	0	0	0	0	0	0	0
Romania	0	0	0	0	0	0.035	0	0	0.035	0.035
Russian Federation	0	0	0	0	0	0	0	0	0	0
San Marino	0	0	0	0	0	0	0	0	0	0
Serbia & Montenegro	0	0	0	0	0	0.003	0	0	0.003	0.003
Slovakia	0	0	0	0	0	0	0	0	0	0
Slovenia	0	0	0	0	0	0	0	0	0	0
Spain	0	0	0	0.001	0.001	0.004	0	0.001	0.007	0.007
Sweden	0	0	0.03	0.043	0.006	0.013	0	0.007	0.091	0.098
Switzerland	0	0	0	0.001	0.003	0.033	0	0	0.037	0.037
Tajikistan	0	0	0	0	0	1.307	0	0	1.307	1.307
The former Yugoslav Republic of Macedonia	0	0	0	0	0	0.109	0	0	0.109	0.109
Turkey	0	0	0	0.078	0.09	0.236	0	0.001	0.405	0.406
Turkmenistan	0	0	0	0	0	0.05	0	0	0.05	0.05
UK	0	0	0.063	0.147	0.021	0.054	0.004	0.019	0.29	0.309
Ukraine	0	0	0	0	0	0	0	0	0	0
Uzbekistan	0	0	0	0	0	0.241	0	0	0.241	0.241
WHO European Region aggregate rates	0	0	0.012	0.036	0.026	0.125	0.001	0.006	0.2	0.206

Chart 8: Annual pregnant carriers of significant variants



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Indicates requirement for information for carriers, and the offer of partner testing. Also indicates annual carriers detectable by neonatal screening.

<i>Country</i>	<i>Alpha zero thalassaemia carrier</i>	<i>Hb AC</i>	<i>Hb AS</i>	<i>Beta thalassaemia carrier</i>	<i>Hb AE</i>	<i>Hb A/other</i>	<i>Total carriers</i>
Albania	0	0	1,409	2,348	0	14	3,771
Andorra	0	0	0	0	0	0	0
Armenia	0	0	0	712	0	10	722
Austria	4	3	34	133	0	23	197
Azerbaijan	0	0	681	6,135	0	34	6,850
Belarus	0	0	0	88	0	26	114
Belgium	21	56	655	386	44	34	1,196
Bosnia and Herzegovina	0	0	0	546	0	10	556
Bulgaria	0	0	0	2,018	0	20	2,038
Croatia	0	0	0	197	0	11	208
Czech Republic	0	0	0	93	0	28	121
Denmark	14	5	44	145	40	19	267
Estonia	0	0	0	12	0	3	15
Faroe Islands	0	0	0	0	0	0	0
Finland	6	2	14	75	16	17	130
France	160	482	4,101	2,319	1,102	227	8,391
Georgia	0	0	0	1,389	0	13	1,402
Germany	69	60	352	1,669	155	212	2,517
Gibraltar	0	0	0	0	0	0	0
Greece	3	2	257	490	4	3	759
Hungary	0	0	0	94	0	28	122
Iceland	0	0	0	4	0	1	5
Ireland	10	12	59	86	8	18	193
Israel	0	0	0	725	0	43	768
Italy	39	95	1,207	17,326	40	162	18,869
Kazakhstan	0	0	0	185	0	74	259
Kyrgyzstan	0	0	0	78	0	31	109
Latvia	0	0	0	20	0	6	26
Liechtenstein	0	0	0	0	0	0	0
Lithuania	0	0	0	30	0	9	39
Luxembourg	0	0	7	25	0	1	33
Malta	0	0	0	117	0	1	118
Monaco	0	0	0	0	0	0	0
Netherlands	14	185	923	826	143	59	2,150
Norway	14	4	45	121	46	16	246
Poland	0	0	0	351	0	105	456
Portugal	3	7	881	1,600	2	32	2,525
Republic of Moldova	0	0	0	36	0	10	46
Romania	0	0	0	2,129	0	63	2,192
Russian Federation	0	0	0	1,474	0	442	1,916
San Marino	0	0	0	0	0	0	0
Serbia & Montenegro	0	0	0	218	0	26	244
Slovakia	0	0	0	51	0	15	66
Slovenia	0	0	0	17	0	5	22
Spain	30	164	474	1,152	8	127	1,955
Sweden	29	10	117	278	80	29	543
Switzerland	26	14	108	303	63	24	538
Tajikistan	0	0	0	8,906	0	53	8,959
The former Yugoslav Republic of Macedonia	0	0	0	539	0	8	547
Turkey	0	15	6,507	24,679	0	443	31,644
Turkmenistan	0	0	0	1,667	0	41	1,708
UK	524	962	3,196	3,244	404	1,300	9,630
Ukraine	0	0	0	409	0	122	531
Uzbekistan	0	0	0	15,601	0	156	15,757
WHO European Region total pregnant carriers	966	2,078	21,071	101,046	2,155	4,154	131,470

Chart 9: Annual pregnancies where both parents carry a significant variant



Country	Risk: hb H disease	Risk: homozygous alpha zero thalassaemia	Risk: hb SC	Risk: hb SS	Risk: hb S/beta thalassaemia	Risk: homozygous beta thalassaemia	Risk: hb E/beta thalassaemia	No risk: harmless combination	Total at-risk pregnancies	Total pregnancies requiring risk assessment
Albania	0	0	0	44	140	120	0	0	304	304
Andorra	0	0	0	0	0	0	0	0	0	0
Armenia	0	0	0	0	0	12	0	0	12	12
Austria	0	0	0	0	0	0	0	0	0	0
Azerbaijan	0	0	0	16	72	448	0	0	536	536
Belarus	0	0	0	0	0	0	0	0	0	0
Belgium	0	0	12	20	4	12	0	4	48	52
Bosnia and Herzegovina	0	0	0	0	0	8	0	0	8	8
Bulgaria	0	0	0	0	0	68	0	0	68	68
Croatia	0	0	0	0	0	0	0	0	0	0
Czech Republic	0	0	0	0	0	0	0	0	0	0
Denmark	0	0	4	4	0	0	0	0	8	8
Estonia	0	0	0	0	0	0	0	0	0	0
Faroe Islands	0	0	0	0	0	0	0	0	0	0
Finland	0	0	0	0	0	0	0	0	0	0
France	0	0	212	316	76	136	0	92	740	832
Georgia	0	0	0	0	0	40	0	0	40	40
Germany	0	0	36	88	16	52	16	56	208	264
Gibraltar	0	0	0	0	0	0	0	0	0	0
Greece	0	0	0	4	64	412	0	0	480	480
Hungary	0	0	0	0	0	0	0	0	0	0
Iceland	0	0	0	0	0	0	0	0	0	0
Ireland	0	0	0	0	0	0	0	0	0	0
Israel	0	0	0	0	0	28	0	0	28	28
Italy	0	0	0	8	88	756	0	0	852	852
Kazakhstan	0	0	0	0	0	0	0	0	0	0
Kyrgyzstan	0	0	0	0	0	0	0	0	0	0
Latvia	0	0	0	0	0	0	0	0	0	0
Liechtenstein	0	0	0	0	0	0	0	0	0	0
Lithuania	0	0	0	0	0	0	0	0	0	0
Luxembourg	0	0	0	0	0	0	0	0	0	0
Malta	0	0	0	0	0	0	0	0	0	0
Monaco	0	0	0	0	0	0	0	0	0	0
Netherlands	0	0	20	36	8	8	4	8	76	84
Norway	0	0	0	8	0	4	4	8	16	24
Poland	0	0	0	0	0	0	0	0	0	0
Portugal	0	0	4	8	8	8	0	0	28	28
Republic of Moldova	0	0	0	0	0	0	0	0	0	0
Romania	0	0	0	0	0	28	0	0	28	28
Russian Federation	0	0	0	0	0	0	0	0	0	0
San Marino	0	0	0	0	0	0	0	0	0	0
Serbia & Montenegro	0	0	0	0	0	0	0	0	0	0
Slovakia	0	0	0	0	0	0	0	0	0	0
Slovenia	0	0	0	0	0	0	0	0	0	0
Spain	0	0	0	0	0	4	0	0	4	4
Sweden	0	0	8	16	0	4	0	0	28	28
Switzerland	0	0	0	0	0	8	0	0	8	8
Tajikistan	0	0	0	0	0	928	0	0	928	928
The former Yugoslav Republic of Macedonia	0	0	0	0	0	8	0	0	8	8
Turkey	0	0	0	460	532	1,396	0	4	2,388	2,392
Turkmenistan	0	0	0	0	0	24	0	0	24	24
UK	0	0	188	440	60	160	12	56	860	916
Ukraine	0	0	0	0	0	0	0	0	0	0
Uzbekistan	0	0	0	0	0	500	0	0	500	500
WHO European Region total pregnancies	0	0	484	1,468	1,068	5,172	36	228	8,228	8,456

Chart 10: Annual conceptions with combinations of significant gene variants



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Indicates (potential) annual affected births, and annual increase in requirements for patient care. Baseline for assessing effects of prevention.

Country	Hb H disease	Homozygous alpha zero thalassaemia	Hb SC	Hb SS	Hb S/beta thalassaemia	Homozygous beta thalassaemia	Hb E/beta thalassaemia	Harmless combinations	Total affected conceptions	Total conceptions with combinations
Albania	0	0	0	11	35	30	0	0	76	76
Andorra	0	0	0	0	0	0	0	0	0	0
Armenia	0	0	0	0	0	3	0	0	3	3
Austria	0	0	0	0	0	0	0	0	0	0
Azerbaijan	0	0	0	4	18	112	0	0	134	134
Belarus	0	0	0	0	0	0	0	0	0	0
Belgium	0	0	3	5	1	3	0	1	12	13
Bosnia and Herzegovina	0	0	0	0	0	2	0	0	2	2
Bulgaria	0	0	0	0	0	17	0	0	17	17
Croatia	0	0	0	0	0	0	0	0	0	0
Czech Republic	0	0	0	0	0	0	0	0	0	0
Denmark	0	0	1	1	0	0	0	0	2	2
Estonia	0	0	0	0	0	0	0	0	0	0
Faroe Islands	0	0	0	0	0	0	0	0	0	0
Finland	0	0	0	0	0	0	0	0	0	0
France	0	0	53	79	19	34	0	23	185	208
Georgia	0	0	0	0	0	10	0	0	10	10
Germany	0	0	9	22	4	13	4	14	52	66
Gibraltar	0	0	0	0	0	0	0	0	0	0
Greece	0	0	0	1	16	103	0	0	120	120
Hungary	0	0	0	0	0	0	0	0	0	0
Iceland	0	0	0	0	0	0	0	0	0	0
Ireland	0	0	0	0	0	0	0	0	0	0
Israel	0	0	0	0	0	7	0	0	7	7
Italy	0	0	0	2	22	189	0	0	213	213
Kazakhstan	0	0	0	0	0	0	0	0	0	0
Kyrgyzstan	0	0	0	0	0	0	0	0	0	0
Latvia	0	0	0	0	0	0	0	0	0	0
Liechtenstein	0	0	0	0	0	0	0	0	0	0
Lithuania	0	0	0	0	0	0	0	0	0	0
Luxembourg	0	0	0	0	0	0	0	0	0	0
Malta	0	0	0	0	0	0	0	0	0	0
Monaco	0	0	0	0	0	0	0	0	0	0
Netherlands	0	0	5	9	2	2	1	2	19	21
Norway	0	0	0	2	0	1	1	2	4	6
Poland	0	0	0	0	0	0	0	0	0	0
Portugal	0	0	1	2	2	2	0	0	7	7
Republic of Moldova	0	0	0	0	0	0	0	0	0	0
Romania	0	0	0	0	0	7	0	0	7	7
Russian Federation	0	0	0	0	0	0	0	0	0	0
San Marino	0	0	0	0	0	0	0	0	0	0
Serbia & Montenegro	0	0	0	0	0	0	0	0	0	0
Slovakia	0	0	0	0	0	0	0	0	0	0
Slovenia	0	0	0	0	0	0	0	0	0	0
Spain	0	0	0	0	0	1	0	0	1	1
Sweden	0	0	2	4	0	1	0	0	7	7
Switzerland	0	0	0	0	0	2	0	0	2	2
Tajikistan	0	0	0	0	0	232	0	0	232	232
The former Yugoslav Republic of Macedonia	0	0	0	0	0	2	0	0	2	2
Turkey	0	0	0	115	133	349	0	1	597	598
Turkmenistan	0	0	0	0	0	6	0	0	6	6
UK	0	0	47	110	15	40	3	14	215	229
Ukraine	0	0	0	0	0	0	0	0	0	0
Uzbekistan	0	0	0	0	0	125	0	0	125	125
WHO European Region total pregnancies	0	0	121	367	267	1,293	9	57	2,057	2,114