

Modell's

Haemoglobinopathologist's

Almanac

Epidemiological Estimates for Haemoglobin Disorders: WHO South East Asian Region by Country

Comprising the following charts and tables:

- Chart 1: Population
- Chart 2: Annual births
- Chart 3: Crude birth rate and infant mortality rate
- Chart 4: Per cent of pregnant women carrying alpha globin gene variants, by variant
- Chart 5: Per cent of pregnant women carrying beta globin gene variants, by variant
- Chart 6: Per cent of pregnant women carrying any haemoglobin gene variant
- Chart 7: Conceptions/1000 with combinations of significant variants
- Chart 8: Annual pregnant carriers of significant variants
- Chart 9: Annual pregnancies where both parents carry a significant variant
- Chart 10: Annual conceptions with combinations of significant gene variants

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, Mauretania, 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, Tadjikistan, 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>

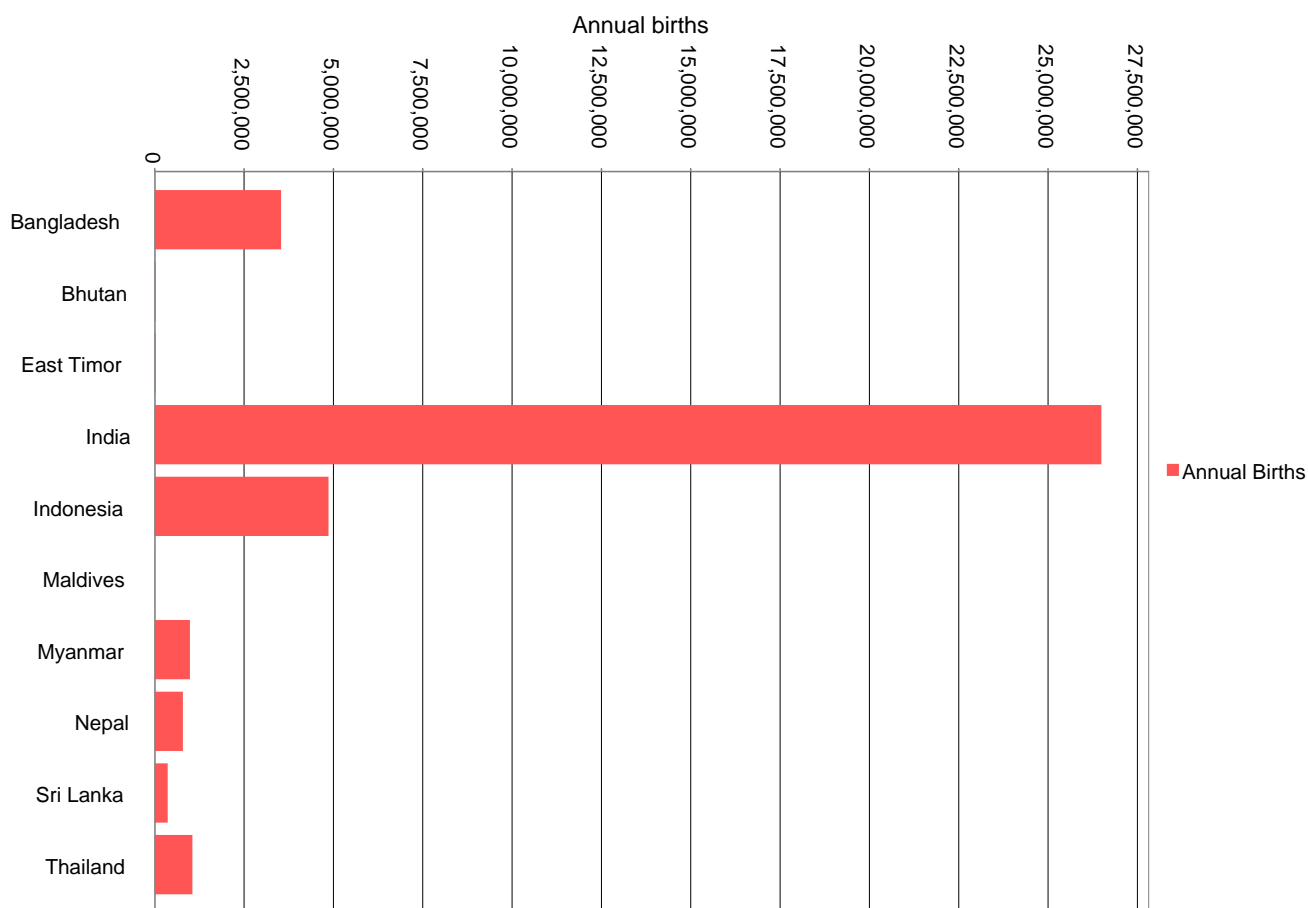
Chart 1: Population



© 2007 University College London

Country	Population number
Bangladesh	128,100,000
Bhutan	716,000
East Timor	871,000
India	1,068,214,000
Indonesia	214,251,000
Maldives	285,000
Myanmar	46,402,000
Nepal	22,904,000
Sri Lanka	19,007,000
Thailand	63,482,000
WHO South East Asian Region population total	1,564,232,000

Chart 2: Annual births

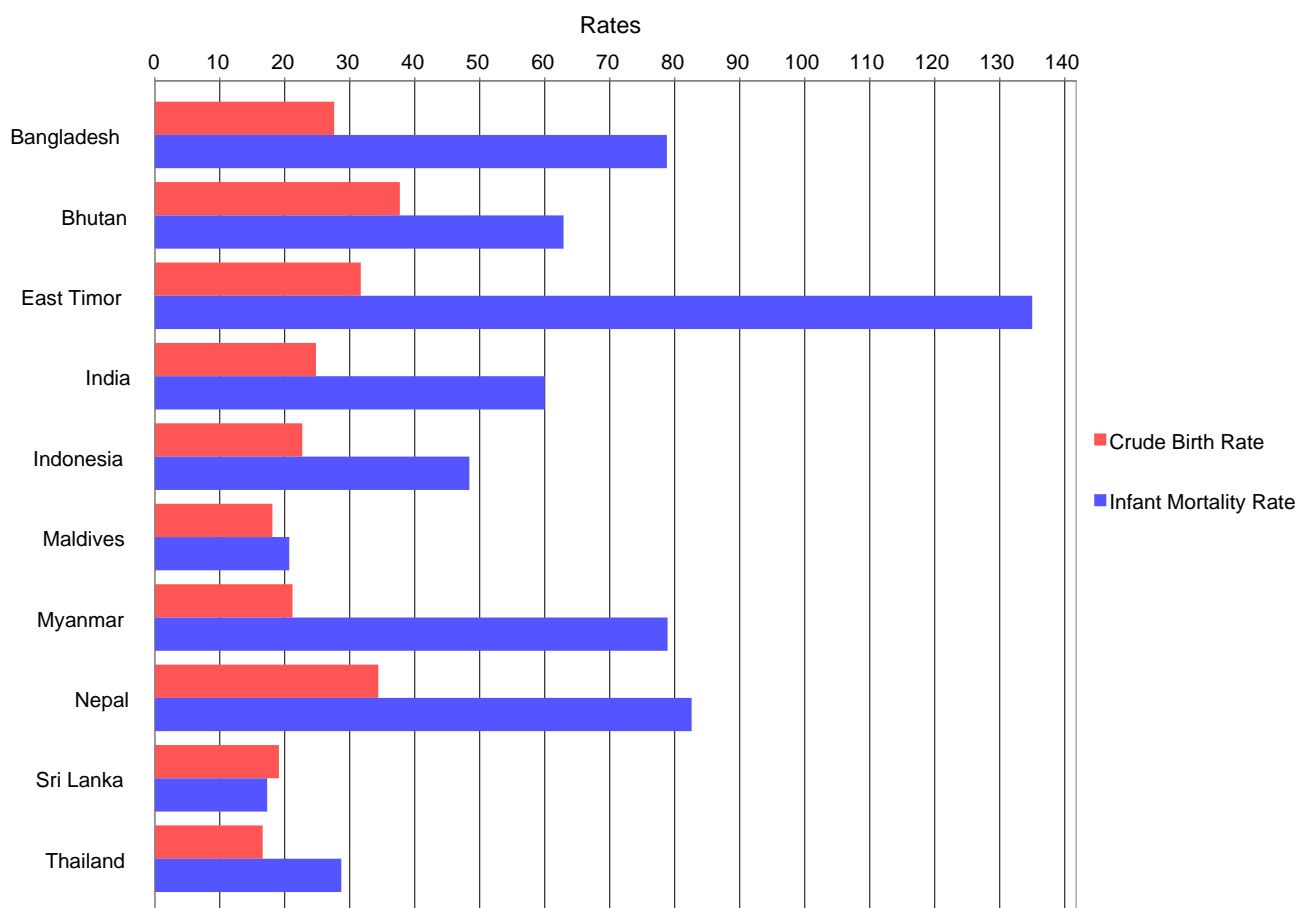


© 2007 University College London

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.

Country	Annual Births
Bangladesh	3,535,560
Bhutan	26,993
East Timor	27,610
India	26,491,707
Indonesia	4,863,497
Maldives	5,158
Myanmar	983,722
Nepal	787,897
Sri Lanka	363,033
Thailand	1,053,801
WHO South East Asian Region total births	38,138,978

Chart 3: Crude birth rate and infant mortality rate

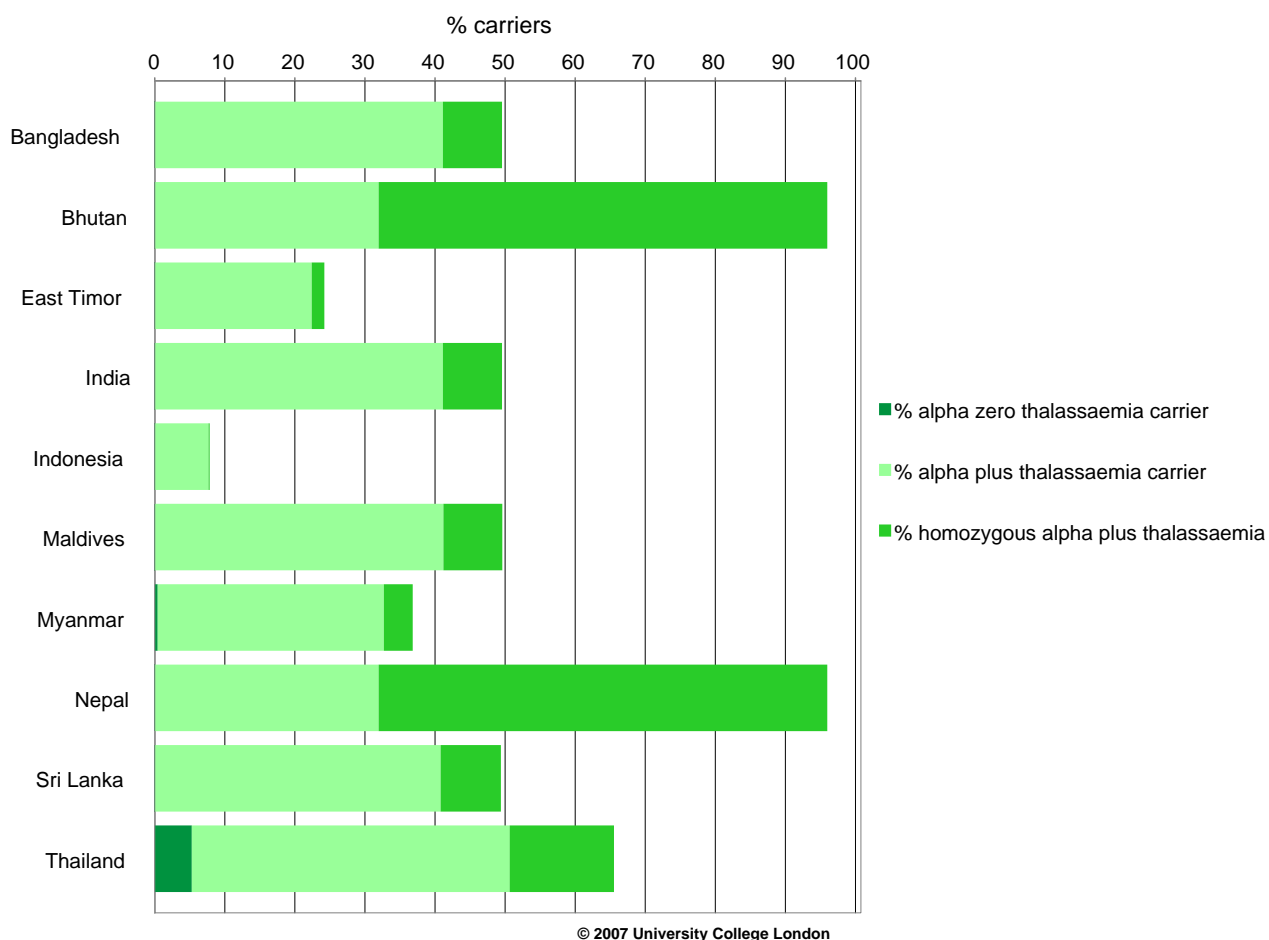


© 2007 University College London

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

Country	Crude Birth Rate	Infant Mortality Rate
Bangladesh	27.6	78.8
Bhutan	37.7	62.9
East Timor	31.7	135
India	24.8	60
Indonesia	22.7	48.4
Maldives	18.1	20.7
Myanmar	21.2	78.9
Nepal	34.4	82.6
Sri Lanka	19.1	17.3
Thailand	16.6	28.7
WHO South East Asian Region aggregate rates	24	59

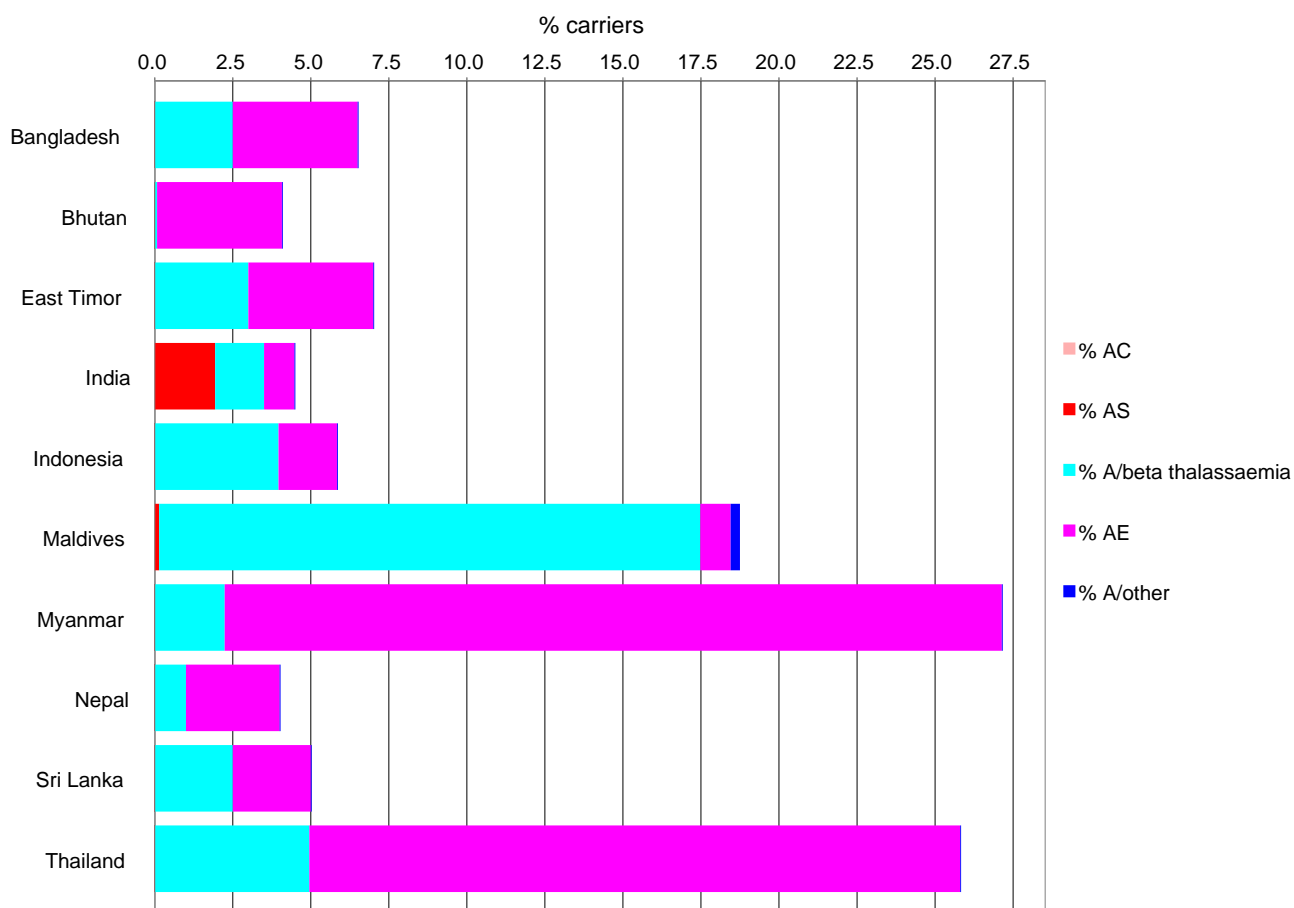
Chart 4: Per cent of pregnant women carrying alpha globin gene variants, by variant



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
Bangladesh	0	41.118	8.441
Bhutan	0	31.952	64.024
East Timor	0	22.405	1.797
India	0	41.118	8.441
Indonesia	0	7.68	0.16
Maldives	0	41.2	8.4
Myanmar	0.422	32.273	4.121
Nepal	0	31.952	64.024
Sri Lanka	0	40.801	8.599
Thailand	5.284	45.361	14.9
WHO South East Asian Region aggregate carrier rates	0.157	36.531	8.636

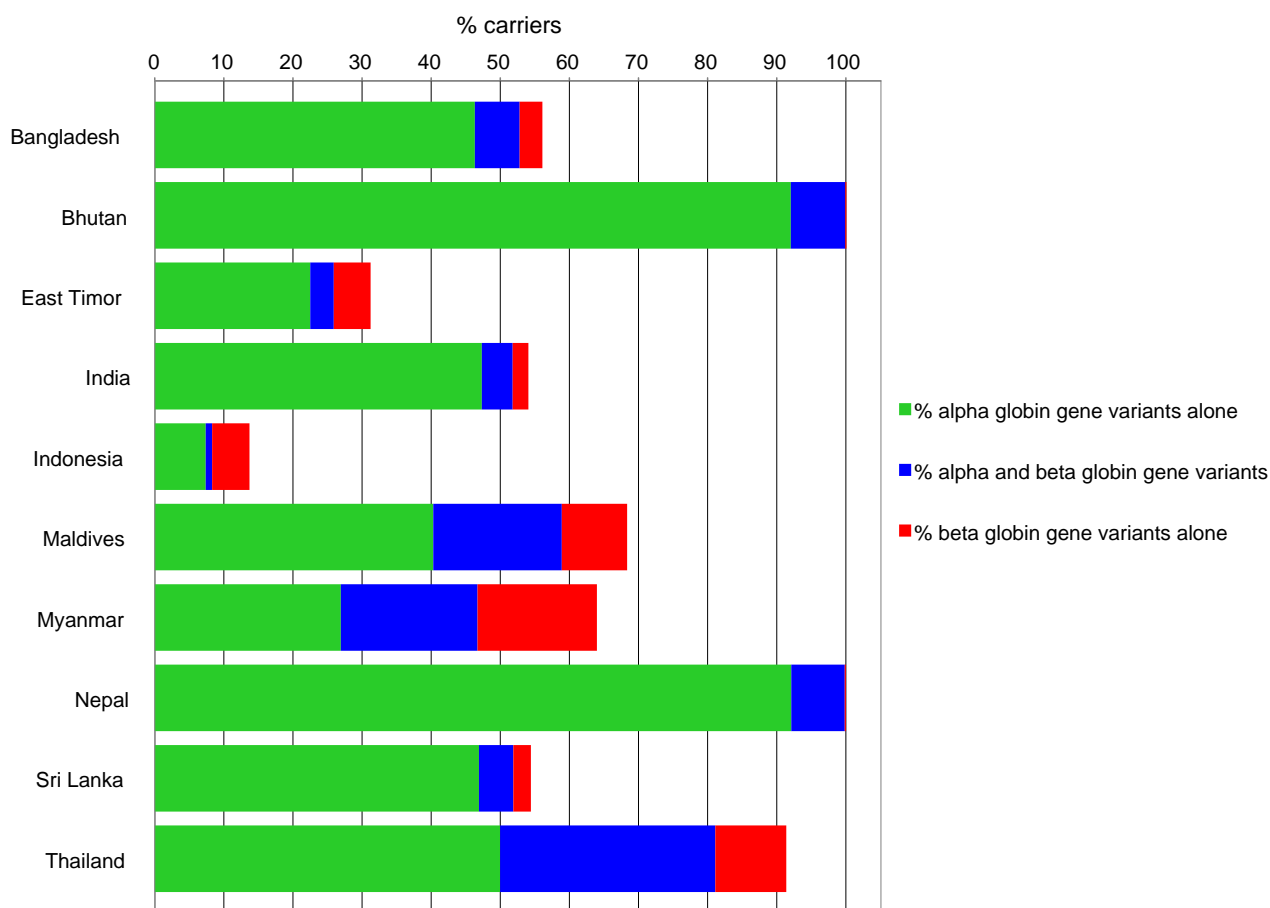
Chart 5: Per cent of pregnant women carrying beta globin gene variants, by variant



© 2007 University College London

Country	% AC	% AS	% A/beta thalassaemia	% AE	% A/other
Bangladesh	0	0	2.5	4	0.03
Bhutan	0	0	0.075	4	0.03
East Timor	0	0	3	4	0.03
India	0	1.936	1.567	0.972	0.03
Indonesia	0	0	3.965	1.872	0.03
Maldives	0	0.14	17.34	0.97	0.3
Myanmar	0	0	2.242	24.896	0.03
Nepal	0	0	1	3	0.03
Sri Lanka	0	0	2.5	2.5	0.03
Thailand	0	0	4.955	20.85	0.03
WHO South East Asian Region aggregate carrier rates	0	1.345	2.07	2.595	0.03

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

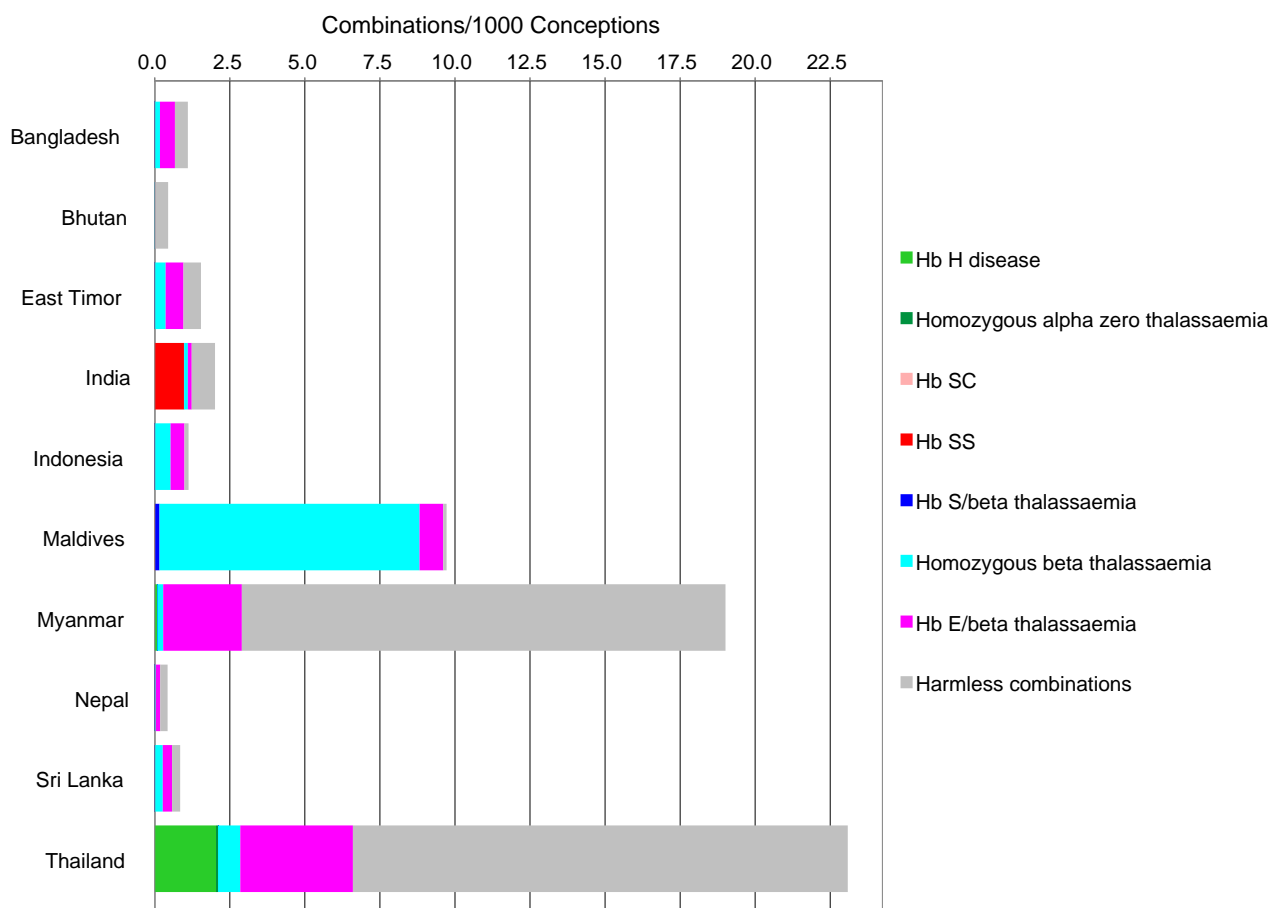


© 2007 University College London

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

Country	% carriers of alpha globin gene variants alone	% carriers of both alpha and beta globin gene variants	% carriers of beta globin gene variants alone	Total % carriers
Bangladesh	46.323	6.472	3.294	56.089
Bhutan	92.036	7.88	0.165	100.081
East Timor	22.501	3.403	5.329	31.233
India	47.327	4.465	2.272	54.064
Indonesia	7.38	0.92	5.407	13.707
Maldives	40.3	18.6	9.45	68.35
Myanmar	26.928	19.775	17.281	63.984
Nepal	92.108	7.736	0.162	100.006
Sri Lanka	46.916	4.97	2.545	54.431
Thailand	49.976	31.137	10.267	91.38
WHO South East Asian Region aggregate carrier rates	42.621	5.407	3.335	51.363

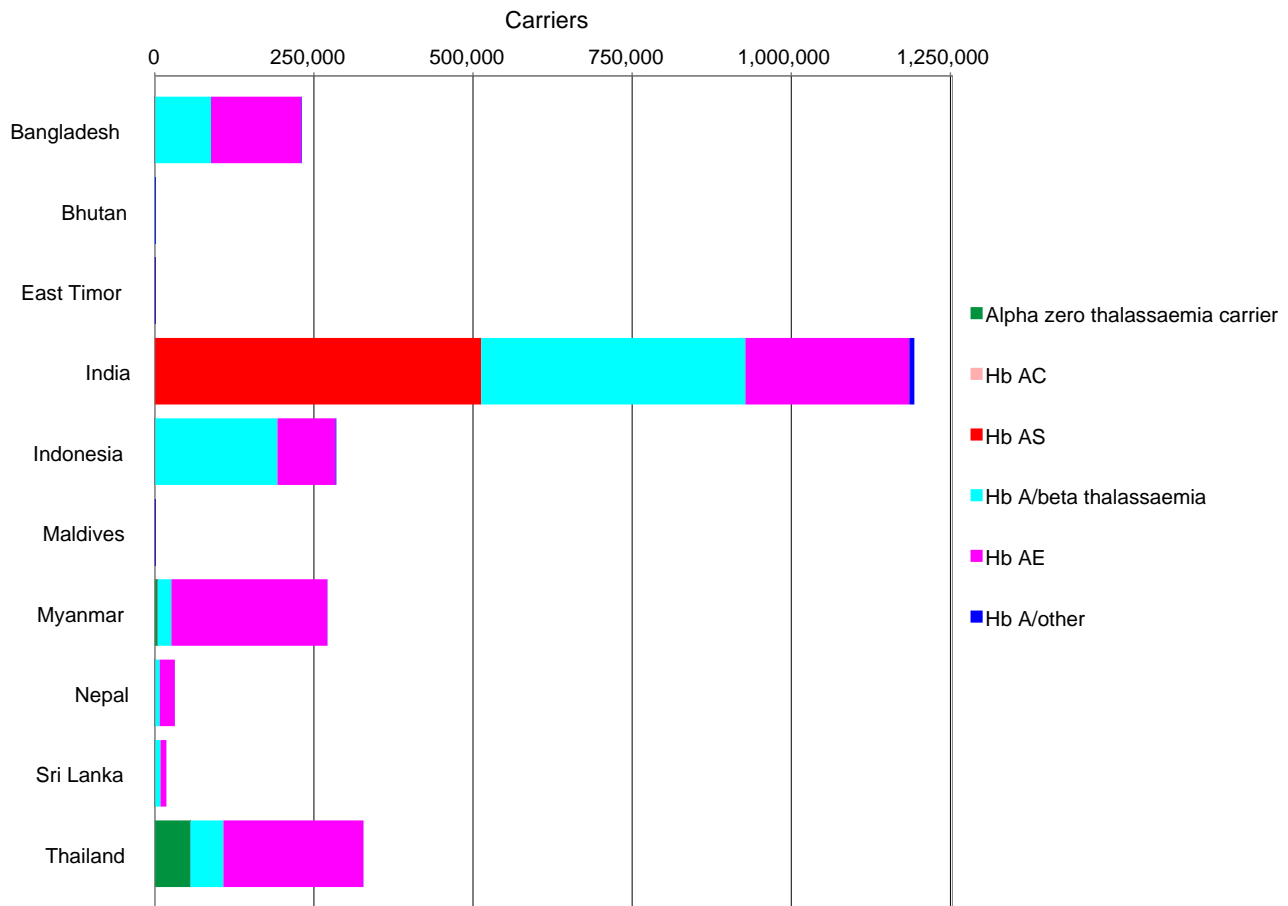
Chart 7: Conceptions/1000 with combinations of significant variants



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
Bangladesh	0	0	0	0	0	0.174	0.499	0.429	0.674	1.103
Bhutan	0	0	0	0	0	0.001	0.015	0.429	0.016	0.445
East Timor	0	0	0	0	0	0.362	0.594	0.583	0.957	1.54
India	0	0	0	0.973	0.01	0.122	0.127	0.775	1.231	2.007
Indonesia	0	0	0	0	0	0.527	0.463	0.136	0.99	1.126
Maldives	0	0	0	0.01	0.15	8.66	0.79	0.112	9.61	9.722
Myanmar	0.086	0	0	0	0	0.196	2.619	16.11	2.9	19.011
Nepal	0	0	0	0	0	0.032	0.15	0.247	0.182	0.429
Sri Lanka	0	0	0	0	0	0.268	0.31	0.268	0.578	0.846
Thailand	2.04	0.07	0	0	0	0.74	3.752	16.483	6.601	23.084
WHO South East Asian Region aggregate rates	0.059	0.002	0	0.676	0.007	0.198	0.371	1.474	1.312	2.786

Chart 8: Annual pregnant carriers of significant variants

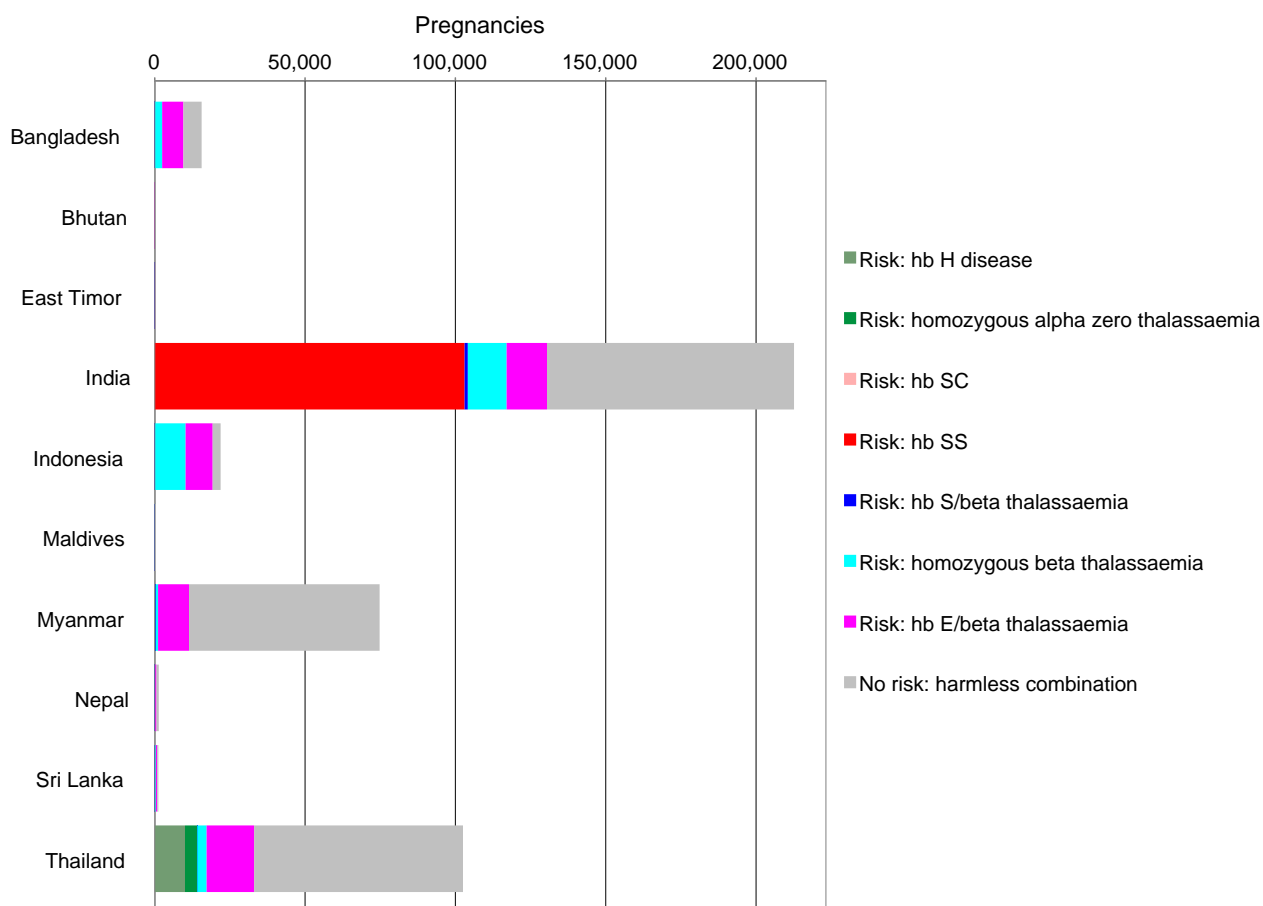


© 2007 University College London

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

Country	Alpha zero thalassaemia carrier	Hb AC	Hb AS	Beta thalassaemia carrier	Hb AE	Hb A/other	Total carriers
Bangladesh	0	0	0	88,389	141,422	1,060	230,871
Bhutan	0	0	0	20	1,079	8	1,107
East Timor	0	0	0	828	1,104	8	1,940
India	0	0	512,793	415,129	257,545	7,947	1,193,414
Indonesia	0	0	0	192,842	91,063	1,459	285,364
Maldives	0	0	7	894	50	15	966
Myanmar	4,150	0	0	22,056	244,907	295	271,408
Nepal	0	0	0	7,878	23,636	236	31,750
Sri Lanka	0	0	0	9,075	9,075	108	18,258
Thailand	55,685	0	0	52,217	219,718	316	327,936
WHO South East Asian Region total pregnant carriers	59,835	0	512,800	789,328	989,599	11,452	2,363,014

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

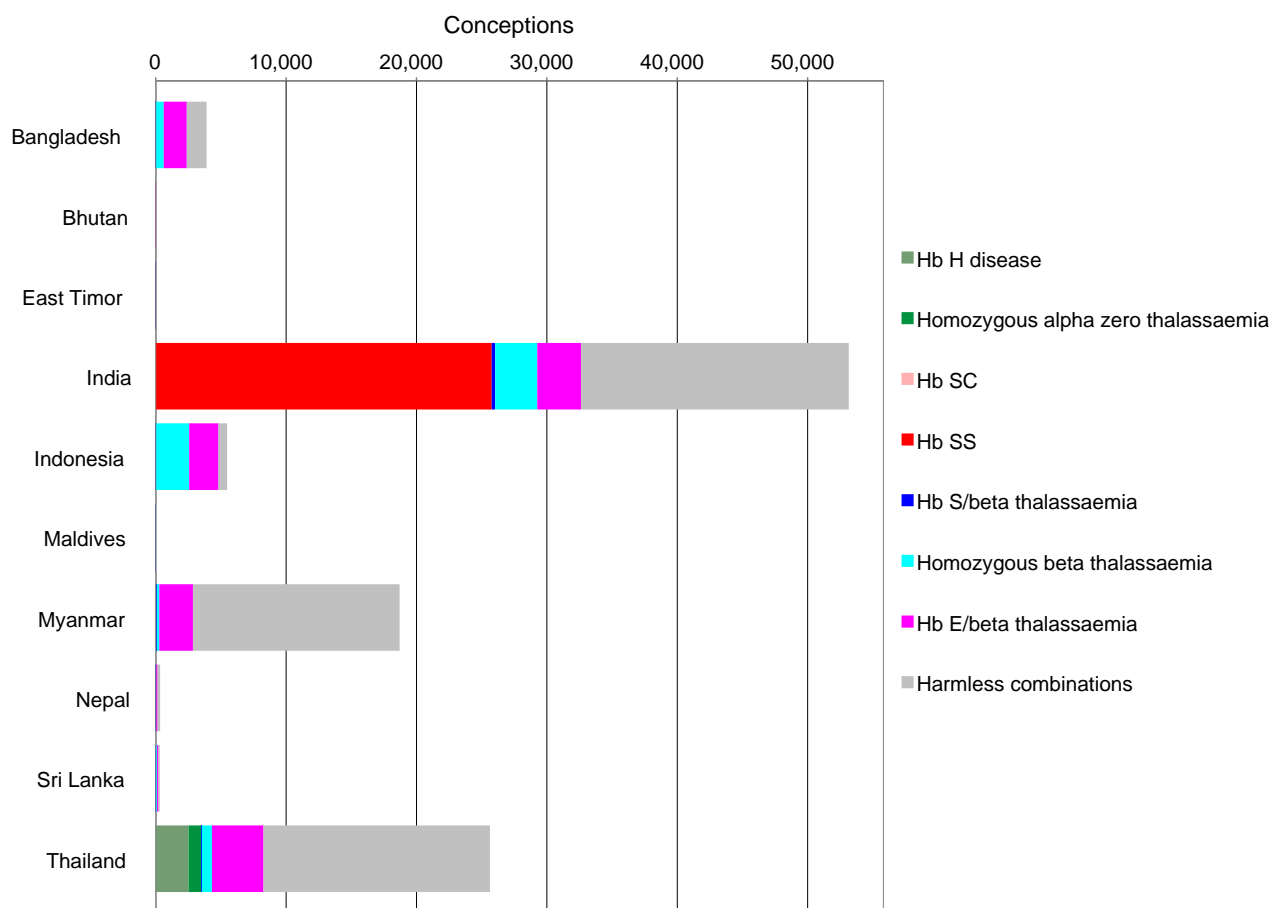


© 2007 University College London

Indicates requirement for expert risk assessment, genetic counselling and the offer of prenatal diagnosis.

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
Bangladesh	0	0	0	0	0	2,464	7,060	6,064	9,524	15,588
Bhutan	0	0	0	0	0	0	0	44	0	44
East Timor	0	0	0	0	0	40	64	64	104	168
India	0	0	0	103,068	1,076	12,900	13,420	82,152	130,464	212,616
Indonesia	0	0	0	0	0	10,256	9,008	2,640	19,264	21,904
Maldives	0	0	0	0	0	176	16	0	192	192
Myanmar	336	0	0	0	0	768	10,304	63,392	11,408	74,800
Nepal	0	0	0	0	0	100	472	776	572	1,348
Sri Lanka	0	0	0	0	0	388	448	388	836	1,224
Thailand	10,060	4,068	0	0	0	3,116	15,812	69,480	33,056	102,536
WHO South East Asian Region total pregnancies	10,396	4,068	0	103,068	1,076	30,208	56,604	225,000	205,420	430,420

Chart 10: Annual conceptions with combinations of significant gene variants



© 2007 University College London

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
Bangladesh	0	0	0	0	0	616	1,765	1,516	2,381	3,897
Bhutan	0	0	0	0	0	0	0	11	0	11
East Timor	0	0	0	0	0	10	16	16	26	42
India	0	0	0	25,767	269	3,225	3,355	20,538	32,616	53,154
Indonesia	0	0	0	0	0	2,564	2,252	660	4,816	5,476
Maldives	0	0	0	0	0	44	4	0	48	48
Myanmar	84	0	0	0	0	192	2,576	15,848	2,852	18,700
Nepal	0	0	0	0	0	25	118	194	143	337
Sri Lanka	0	0	0	0	0	97	112	97	209	306
Thailand	2,515	1,017	0	0	0	779	3,953	17,370	8,264	25,634
WHO South East Asian Region total pregnancies	2,599	1,017	0	25,767	269	7,552	14,151	56,250	51,355	107,605