

**PHG Needs Assessment Calculator****Timor-Leste****Newborn screening**

Welcome to the PHG Health Needs Assessment Calculator for Newborn Screening. The contents of this file are listed below.

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**Timor-Leste****Shared Data****Demographic, maternal health and socio-economic indicators**

**Please read first! If you have already completed a needs assessment for a different topic in this country, you will be able to copy the Demography information from that Calculator into here. The information should be the same.**

**By default, the Toolkit contains information at the national level.**

**If you would like to use a different population, then replace country information with that of your specific population of interest.**

Number of persons by age-group and sex	Estimates			Your estimates			Chosen estimates		
Age group	Male	Female	Total	Male	Female	Total	Male	Female	Total
0-4 years	77720	73024	150744			0			0
5-9 years	66661	62759	129420			0			0
10-14 years	61422	57225	118647			0			0
15-19 years	47953	47321	95274			0			0
20-24 years	37640	38061	75701			0			0
25-29 years	28366	28772	57138			0			0
30-34 years	32227	30183	62410			0			0
35-39 years	24894	23906	48800			0			0
40-44 years	22513	23433	45946			0			0
45-49 years	16917	17403	34320			0			0
50-54 years	16651	16282	32933			0			0
55-59 years	9910	9295	19205			0			0
60-64 years	10613	9903	20516			0			0
65+ years	16432	15712	32144			0			0
Total	0	0	923198	0	0	0	0	0	0
Female population aged 15-44 years		0			0			0	
Data year	2004 reported in 2010								
Source, Year	UN 2011								

**Ethnicity. Please enter data for the main ethnic groups if you are working with a population that is different from that of the country.**

Ethnic group	Number	% population

<b>Fertility and mortality</b>	<b>Estimate</b>	<b>Source, Year</b>	<b>Your estimate</b>	<b>Source, Year</b>	<b>Chosen estimate</b>	<b>Source, Year</b>
Crude birth rate: live births (LB) per year / 1000 population	25	Unicef, 2007				
Still birth rate (SB): Still births (SB) per year / 1000 population	9	WHO, 2009				
Total births in 1000s (LB+SB) per year	3.00	Unicef, 2007				
Infant mortality rate: infant deaths / 1000 LB / year	46.00	UNICEF				
Under-5 mortality rate: U5 deaths / 1000 LB / year	55.00	UNICEF (2011), 2010				
Percentage births in women >35 years						
Life expectancy at birth (yrs)	71	WHO, 2009				
% of marriages consanguineous						

<b>Maternal health</b>	<b>Estimate</b>	<b>Source, Year</b>	<b>Your estimate</b>	<b>Source, Year</b>	<b>Chosen estimate</b>	<b>Source, Year</b>
Prenatal visits – at least 1 visit (%)	99	WHO, 2004				
Prenatal visits – at least 4 visits (%)						
Births attended by skilled health personnel (%)	98	WHO, 2005				
Contraception prevalence rate (%)						
Unmet need for family planning (%)						
Total fertility rate	3.9	WHO, 2009				
% home births						
% births at health care services						
<b>Newborn health</b>	<b>Estimate</b>	<b>Source, Year</b>	<b>Your estimate</b>	<b>Source, Year</b>	<b>Chosen estimate</b>	<b>Source, Year</b>
Number of neonatal examinations by SBA / trained staff						
% neonatal examinations by SBA/ trained staff						

<b>Socio-economic indicators</b>	<b>Estimate</b>	<b>Source, Year</b>	<b>Your estimate</b>	<b>Source, Year</b>	<b>Chosen estimate</b>	<b>Source, Year</b>
Gross national income per capita (PPP int. \$)	3980	WHO, 2008				
% population living on < US\$1 per day						
Birth registration coverage (%)	>90	WHO, 2006				
Death registration coverage (%)						

LB = live births

PPP = purchasing power parity

SBA = skilled birth attendant

**Timor-Leste**  
**Shared Data**  
**Health Services Data**

**Please read first!** If you have already completed a needs assessment for a different topic in this country, you will be able to copy the Health Services information from that Calculator into here. The information should be the same.

This section provides health-service-related information for your country.

**By default, the Toolkit contains information at the national level.**

**If you would like to use a different population, then replace country information with that of your specific population of interest.**

<b>Health Expenditure</b>	<b>Estimate</b>	<b>Source, Year</b>	<b>Your estimate</b>	<b>Source, Year</b>	<b>Chosen estimate</b>	<b>Source, Year</b>
Per capita total expenditure on health (PPP int. \$)	236	WHO, 2009				
Total expenditure on health as percentage of GDP	6.2	WHO, 2009				
Per capita government expenditure on health (PPP int. \$)	186	WHO, 2009				
External resources for health as percentage of total expenditure on health	4.2	WHO, 2009				
General government expenditure on health as percentage of total expenditure on health	78.8	WHO, 2009				
Out-of-pocket expenditure as percentage of private expenditure on health	84.7	WHO, 2009				
Private expenditure on health as percentage of total expenditure on health	21.2	WHO, 2009				
General government expenditure on health as percentage of total government expenditure	14.5	WHO, 2009				

<b>Health Workforce</b>	<b>Estimate</b>	<b>Source, Year</b>	<b>Your estimate</b>	<b>Source, Year</b>	<b>Chosen estimate</b>	<b>Source, Year</b>
Number of nursing and midwifery personnel	302	WHO, 2007				
Nursing and midwifery personnel density (per 10,000 population)	29.3	WHO, 2007				
Number of physicians	30	WHO, 2002				
Physician density (per 10 000 population)	2.912	WHO, 2002				
Number of obstetricians						
Number of paediatricians						
Number of paediatric surgeons						
Number of paediatric cardiac surgeons						
Number of paediatric neurosurgeons						
Number of clinical geneticists						
Number of genetic counsellors						
Number of community health workers						
Number of skilled birth attendants (SBA)						
Density of SBA						

Number of lab staff providing cytogenetic testing						
Number of lab staff providing molecular genetics						
Number of lab staff providing biochemical tests for genetics						
Number of skilled health attendants						

<b>Infrastructure</b>	<b>Estimate</b>	<b>Source, Year</b>	<b>Your estimate</b>	<b>Source, Year</b>	<b>Chosen estimate</b>	<b>Source, Year</b>
Number of maternity units						
Number of services providing specialised care for people with CD						
Number of family planning services						
Number of preconception services						
Number of services providing prenatal care						
Number of services providing newborn care						
Number of facilities providing genetic services						
Number of laboratories providing cytogenetics						
Number of laboratories providing molecular genetics						
Number of laboratories providing biochemical tests for genetics						
Number of facilities for safe terminations of pregnancies for fetal defects						

PPP = purchasing power parity

GDP = gross domestic product

SBA = skilled birth attendant

CD = congenital disorders

**Timor-Leste****Newborn screening****Existing screening programmes for congenital disorders**

Condition	Tick if NBS programme exists	Tick if included in physical examination	Indicate whether NBS is provided at national or sub-national level	Condition prevalence per 1000 newborns	Prevalence variation and high-risk populations
Eye problems					
Signs of heart disease					
Developmental dysplasia of hips					
Genital anomalies (e.g. undescended testicles)					
Orofacial clefts					
Dysmorphologies					
Hearing loss					
Congenital hypothyroidism					
G6PD deficiency					
PKU					
Cystic fibrosis					
Thalassaemias					
Sickle cell disease					
MCADD					
CAH					
Other					

NBS = newborn screening

G6PD = glucose-6-phosphate dehydrogenase

PKU = phenylketonuria

CAH= congenital adrenal hyperplasia

MCADD = medium-chain acyl-CoA dehydrogenase deficiency

**Timor-Leste****Newborn screening****Details of newborn screening programmes**

Condition	Age at screen	Coverage (%)	Coverage variation and high-risk populations	Estimated proportion of Target affected newborns detected	Target coverage (%)
<b>Newborn physical examination</b>					
Basic examination*					
Examination for gross abnormalities*					
Detailed physical examination					
<b>Newborn hearing screening</b>					
Crude screening					
Equipment based screening					
<b>Newborn bloodspot screening</b>					
Congenital hypothyroidism					
PKU					
Cystic fibrosis					
Sickle cell disease					
G6PD deficiency					
MCADD					
CAH					
Other					

PKU = phenylketonuria

G6PD = glucose-6-phosphate dehydrogenase

MCADD = medium-chain acyl-CoA dehydrogenase deficiency

CAH= congenital adrenal hyperplasia

\* As defined in the Background document section titled Newborn Screening Tests

**Timor-Leste****Newborn screening****Effects of NBS and treatment on congenital hypothyroidism**

Baseline birth prevalence of CHT, per 1000 total births*		
Variables		
Coverage of newborn screening		Range: 0 to 1
Proportion of positive-screened patients receiving diagnosis treatment		Range: 0 to 1
Effectiveness of treatment		Range: 0 to 1
Results		
Proportional reduction of uncontrolled cases of CHT through NBS and treatment <sup>1</sup>	0	
Prevalence of uncontrolled CHT after newborn screening and treatment, per 1000 total births <sup>2</sup>	0	

LB = live births

CHT = congenital hypothyroidism

NBS = newborn screening

\* If you don't have data on birth prevalence but do have data on screening, you can estimate birth prevalence by combining the proportion screened positive with the number of total births. (This assumes that screening is randomly distributed in the population).

<sup>1</sup>Coverage of newborn screening X Proportion of screen-positive cases receiving treatment X Effectiveness of treatment

<sup>2</sup>Baseline birth prevalence – (Proportional reduction of uncontrolled cases of CHT X Baseline birth prevalence)



**Timor-Leste****Newborn screening****Effects of NBS and treatment on G6PD deficiency**

Baseline birth prevalence of G6PD deficiency, per 1000 LB		
Variables		
Coverage of newborn screening		Range: 0 to 1
Proportion of positive-screened patients receiving treatment		Range: 0 to 1
Effectiveness of treatment		Range: 0 to 1
Results		
Proportional reduction of uncontrolled cases through NBS and treatment <sup>1</sup>	0	
Prevalence of uncontrolled G6PD deficiency after newborn screening and treatment, per 1000 LB <sup>2</sup>	0	

LB = live births

NBS = newborn screening

G6PD = glucose-6-phosphate dehydrogenase

\* If you don't have data on birth prevalence but do have data on screening, you can estimate birth prevalence by combining the proportion screened positive with the number of total births. (This assumes that screening is randomly distributed in the population).

<sup>1</sup>Coverage of newborn screening X Proportion of screen-positive cases receiving treatment X Effectiveness of treatment

<sup>2</sup>Baseline birth prevalence – (Proportional reduction of uncontrolled cases of G6PD X Baseline birth prevalence)

**Timor-Leste****Newborn screening****Effects of NBS and treatment on RHD**

Baseline birth prevalence of RHD, per 1000 LB		
Variables		
Coverage of newborn screening		Range: 0 to 1
Proportion of positive-screened patients receiving treatment		Range: 0 to 1
Effectiveness of treatment		Range: 0 to 1
Results		
Proportional reduction of uncontrolled cases through NBS and treatment <sup>1</sup>	0	
Prevalence of uncontrolled RHD deficiency after newborn screening and treatment, per 1000 LB <sup>2</sup>	0	

LB = live births

NBS = newborn screening

RHD = Rhesus Haemolytic Disease of Newborn

\* If you don't have data on birth prevalence but do have data on screening, you can estimate birth prevalence by combining the proportion screened positive with the number of total births. (This assumes that screening is randomly distributed in the population).

<sup>1</sup>Coverage of newborn screening X Proportion of screen-positive cases receiving treatment X Effectiveness of treatment

<sup>2</sup>Baseline birth prevalence – (Proportional reduction of uncontrolled cases of RHD X Baseline birth prevalence)

**Timor-Leste****Newborn screening****Effects of NBS and management on sickle cell disease**

Baseline birth prevalence of sickle cell disease, per 1000 LB		
Variables		
Coverage of newborn screening		Range: 0 to 1
Proportion of positive-screened patients referred for management		Range: 0 to 1
Effectiveness of management		Range: 0 to 1
Results		
Proportional reduction in unmanaged cases of SCD through NBS and treatment <sup>1</sup>	0	
Prevalence of unmanaged sickle cell disease after newborn screening and treatment, per 1000 LB <sup>2</sup>	0	

LB = live births

SCD = sickle cell disease

NBS = newborn screening

\* If you don't have data on birth prevalence but do have data on screening, you can estimate birth prevalence by combining the proportion screened positive with the number of total births. (This assumes that screening is randomly distributed in the population).

<sup>1</sup>Coverage of newborn screening X Proportion of screen-positive cases receiving treatment X Effectiveness of treatment

<sup>2</sup>Baseline birth prevalence – (Proportional reduction of unmanaged cases of SCD X Baseline birth prevalence)

**Timor-Leste****Newborn screening****Effects of NBS and management on thalassaemias**

Baseline birth prevalence of thalassaemias, per 1000 LB		
Variables		
Coverage of newborn screening		Range: 0 to 1
Proportion of screen-positive patients referred for treatment		Range: 0 to 1
Effectiveness of management		Range: 0 to 1
Results		
Proportional reduction of prevalence of unmanaged thalassaemias through NBS and treatment <sup>1</sup>	0	
Prevalence of unmanaged thalassaemias after newborn screening and treatment, per 1000 LB <sup>2</sup>	0	

LB = live births

NBS = newborn screening

\* If you don't have data on birth prevalence but do have data on screening, you can estimate birth prevalence by combining the proportion screened positive with the number of total births. (This assumes that screening is randomly distributed in the population).

<sup>1</sup>Coverage of newborn screening X Proportion of screen-positive cases receiving treatment  
X Effectiveness of treatment

<sup>2</sup>Baseline birth prevalence – (Proportional reduction of unmanaged cases of thalassaemia X  
Baseline birth prevalence)

**Timor-Leste****Newborn screening****Effects of NBS and treatment on orofacial clefts**

Baseline birth prevalence of orofacial clefts, per 1000 LB		
Variables		
Coverage of newborn screening		Range: 0 to 1
Proportion of screen-positive patients receiving treatment		Range: 0 to 1
Effectiveness of treatment		Range: 0 to 1
Results		
Proportional reduction of prevalence of untreated OFCs through NBS and treatment <sup>1</sup>	0	
Prevalence of untreated OFCs after newborn screening and treatment, per 1000 LB <sup>2</sup>	0	

LB = live births

OFCs = orofacial clefts

NBS = newborn screening

\* If you don't have data on birth prevalence but do have data on screening, you can estimate birth prevalence by combining the proportion screened positive with the number of total births. (This assumes that screening is randomly distributed in the population).

<sup>1</sup>Coverage of newborn screening X Proportion of screen-positive cases receiving treatment X Effectiveness of treatment

<sup>2</sup>Baseline birth prevalence – (Proportional reduction of untreated cases of OFC X Baseline birth prevalence)

**Timor-Leste****Newborn screening****Effects of NBS and treatment on phenylketonuria**

Baseline birth prevalence of PKU, per 1000 LB		
Variables		
Coverage of newborn screening		Range: 0 to 1
Proportion of positive-screened patients receiving treatment		Range: 0 to 1
Effectiveness of treatment		Range: 0 to 1
Results		
Proportional reduction of prevalence of clinical cases of PKU through NBS and treatment <sup>1</sup>	0	
Prevalence of symptomatic PKU after newborn screening and treatment, per 1000 LB <sup>2</sup>	0	

LB = live births

PKU = phenylketonuria

NBS = newborn screening

\* If you don't have data on birth prevalence but do have data on screening, you can estimate birth prevalence by combining the proportion screened positive with the number of total births. (This assumes that screening is randomly distributed in the population).

<sup>1</sup>Coverage of newborn screening X Proportion of screen-positive cases receiving treatment X Effectiveness of treatment

<sup>2</sup>Baseline birth prevalence – (Proportional reduction of prevalence of clinical cases of PKU X Baseline birth prevalence)

**Timor-Leste****Newborn screening****Effects of NBS and management on cystic fibrosis**

Baseline birth prevalence of cystic fibrosis, per 1000 LB		
Variables		
Coverage of newborn screening		Range: 0 to 1
Proportion of positive-screened patients referred for management		Range: 0 to 1
Effectiveness of management		Range: 0 to 1
Results		
Proportional reduction of prevalence of unmanaged cystic fibrosis through NBS and treatment <sup>1</sup>	0	
Prevalence of unmanaged cystic fibrosis after newborn screening and treatment, per 1000 LB <sup>2</sup>	0	

LB = live births

NBS = newborn screening

\* If you don't have data on birth prevalence but do have data on screening, you can estimate birth prevalence by combining the proportion screened positive with the number of total births. (This assumes that screening is randomly distributed in the population).

<sup>1</sup>Coverage of newborn screening X Proportion of positive-screened patients referred for management X Effectiveness of management

<sup>2</sup>Baseline birth prevalence – (Proportional reduction of prevalence of unmanaged cases X Baseline birth prevalence)