

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 Age group	Estimates			Your estimates			Chosen estimates		
	Male	Female	Total	Male	Female	Total	Male	Female	Total
0-4 years	825789	830931	1656720			0			0
5-9 years	729181	731901	1461082			0			0
10-14 years	601279	604367	1205646			0			0
15-19 years	513320	556676	1069996			0			0
20-24 years	416083	492589	908672			0			0
25-29 years	361901	379247	741148			0			0
30-34 years	282439	275434	557873			0			0
35-39 years	211356	218631	429987			0			0
40-44 years	161179	164597	325776			0			0
45-49 years	122486	122834	245320			0			0
50-54 years	97850	105762	203612			0			0
55-59 years	71905	72933	144838			0			0
60-64 years	62678	68797	131475			0			0
65+ years	136844	118436	255280			0			0
Total	0	0	9337425	0	0	0	0	0	0
Female population aged 15-44 years		0			0			0	
Data year	2000 reported in 2003								
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

Fertility and mortality	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Crude birth rate: live births (LB) / year / 1000 population	38.15	Unicef, 2013				
Stillbirth rate (SB): Still births (SB) / year / 1000 total births	14.27	WHO, 2009				
Total births in 1000s (LB+SB) per year	44	Unicef, 2013				
Infant mortality rate: infant deaths / 1000 LB / year	45.80	Unicef, 2013				
Under-5 mortality rate: U5 deaths / 1000 LB / year	54.10	Unicef, 2013				
Percentage births in women >35 years						
Life expectancy at birth (yrs)	62.48	Unicef, 2013				
% of marriages consanguineous						

Maternal health	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Prenatal visits – at least 1 visit (%)	84.4	Unicef, 2013				
Prenatal visits – at least 4 visits (%)	55.1	Unicef, 2013				
Births attended by skilled health personnel (%)	29.3	Unicef, 2013				
Contraception prevalence rate (%)	22.3	Unicef, 2013				
Unmet need for family planning (%)						
Total fertility rate	6.11	Unicef, 2013				
% home births						
% births at health care services	22.10	Unicef, 2013				
Newborn health	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Number of neonatal examinations by SBA / trained staff						
% neonatal examinations by SBA/ trained staff						

Socio-economic indicators	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Gross national income per capita (PPP int. \$)	5210	Unicef, 2013				
% population living on < US\$1 per day		Unicef, 2013				
Birth registration coverage (%)	55.2	WHO 2009-				
Death registration coverage (%)		WHO 2010				

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.

Health Expenditure	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Per capita total expenditure on health (PPP int. \$)	82.1	WHO 2011				
Total expenditure on health as percentage of GDP	5.1	WHO 2011				
Per capita government expenditure on health (PPP int. \$)	58.7	WHO 2011				
External resources for health as percentage of total expenditure on health	0.4	WHO 2011				
General government expenditure on health as percentage of total expenditure on health	71.5	WHO 2011				
Out-of-pocket expenditure as percentage of private expenditure on health	14.2	WHO 2011				
Private expenditure on health as percentage of total expenditure on health	28.5	WHO 2011				
General government expenditure on health as percentage of total government expenditure	2.9	WHO 2011				

Health Workforce	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
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						

Infrastructure	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
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 affected newborns detected	Target coverage (%)
Newborn physical examination					
Basic examination*					
Examination for gross abnormalities*					
Detailed physical examination					
Newborn hearing screening					
Crude screening					
Equipment based screening					
Newborn bloodspot screening					
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 ¹	0	
Prevalence of uncontrolled CHT after newborn screening and treatment, per 1000 total births ²	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).

¹Coverage of newborn screening X Proportion of screen-positive cases receiving treatment X Effectiveness of treatment

²Baseline 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 ¹	0	
Prevalence of uncontrolled G6PD deficiency after newborn screening and treatment, per 1000 LB ²	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).

¹Coverage of newborn screening X Proportion of screen-positive cases receiving treatment X Effectiveness of treatment

²Baseline 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 ¹	0	
Prevalence of uncontrolled RHD deficiency after newborn screening and treatment, per 1000 LB ²	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).

¹Coverage of newborn screening X Proportion of screen-positive cases receiving treatment X Effectiveness of treatment

²Baseline 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 ¹	0	
Prevalence of unmanaged sickle cell disease after newborn screening and treatment, per 1000 LB ²	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).

¹Coverage of newborn screening X Proportion of screen-positive cases receiving treatment X Effectiveness of treatment

²Baseline birth prevalence – (Proportional reduction of unmanaged cases of SCD X Baseline birth prevalence)

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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 ¹	0	
Prevalence of unmanaged thalassaemias after newborn screening and treatment, per 1000 LB ²	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).

¹Coverage of newborn screening X Proportion of screen-positive cases receiving treatment X Effectiveness of treatment

²Baseline birth prevalence – (Proportional reduction of unmanaged cases of thalassaemia X Baseline birth prevalence)

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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 ¹	0	
Prevalence of untreated OFCs after newborn screening and treatment, per 1000 LB ²	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).

¹Coverage of newborn screening X Proportion of screen-positive cases receiving treatment X Effectiveness of treatment

²Baseline 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 ¹	0	
Prevalence of symptomatic PKU after newborn screening and treatment, per 1000 LB ²	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).

¹Coverage of newborn screening X Proportion of screen-positive cases receiving treatment X Effectiveness of treatment

²Baseline 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 ¹	0	
Prevalence of unmanaged cystic fibrosis after newborn screening and treatment, per 1000 LB ²	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).

¹Coverage of newborn screening X Proportion of positive-screened patients referred for management X Effectiveness of management

²Baseline birth prevalence – (Proportional reduction of prevalence of unmanaged cases X Baseline birth prevalence)