

**PHG Needs Assessment Calculator****Timor-Leste****Sickle Cell Disease**

Welcome to the PHG Health Needs Assessment Calculator for Sickle Cell Disease. The contents of this file are listed below.

Full name of the sheet	Short name
Country demographic, maternal health and socioeconomic indicators	Demography
Country health service data	HealthServices
SCD Epidemiology 1.1: Country epidemiology	SCD-E1.1
SCD Epidemiology 1.2: International comparison	SCD-E1.2
SCD Epidemiology 2.1: Data on affected pregnancies: Research studies	SCD-E2.1
SCD Epidemiology 2.2: Data on affected pregnancies: Surveillance	SCD-E2.2
SCD Epidemiology 2.3: Data on affected pregnancies: Other sources	SCD-E2.3
SCD Epidemiology 2.4: Summary of affected pregnancies	SCD-E2.4
SCD Epidemiology 2.5: Sub-population variation in affected pregnancies	SCD-E2.5
SCD Epidemiology 3.1: Mortality data: Research studies	SCD-E3.1
SCD Epidemiology 3.2: Mortality data: Vital registration data	SCD-E3.2
SCD Epidemiology 3.3: Mortality data: Other sources	SCD-E3.3
SCD Epidemiology 3.4: Summary mortality estimates	SCD-E3.4
SCD Epidemiology 3.5: Sub-population variation in mortality	SCD-E3.5
SCD Epidemiology 4.1: Population prevalence: Research studies	SCD-E4.1
SCD Epidemiology 4.2: Population prevalence: Other sources	SCD-E4.2
SCD Epidemiology 4.3: Summary of population prevalence	SCD-E4.3
SCD Epidemiology 4.4: Sub-population prevalence variation	SCD-E4.4
SCD Interventions 1: Newborn screening and management	SCD-Interv1
SCD Needs Assessment Calculator 1: Quantitative baseline	SCD-NA1
SCD Needs Assessment Calculator 3: Quantitative assessment of interventions	SCD-NA3

(There is no sheet SCD-NA2.)

**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			-			-	
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) / year / 1000 population	25	Unicef, 2007				
Still birth rate: still births (SB) / year / 1000 total births	9	WHO, 2009				
Total births in 1000s (LB+SB) per year	3	Unicef, 2007				
Infant mortality rate: infant deaths / 1000 LB / year	46	UNICEF				
Under-5 mortality rate: U5 deaths / 1000 LB / year	55	(2011), 2010				
Percentage births in women >35 years		(2011), 2010				
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****Sickle Cell Disease****SCD Epidemiology 1.1: Country epidemiology**

Epidemiological indicator	Your estimates	Range	PHGDB minimum estimates	Chosen estimates	Range	Source
<b>Year of estimate</b>						
<b>Prevalence at birth and by age-group (/1000)</b>						
Live birth prevalence (LB)			0.00			
Stillbirth prevalence (SB)			0.00			
Total birth prevalence (LB+SB)			0.00			
All age groups						
<1 year olds						
1-4 year olds						
5-14 year olds						
15-44 year olds						
45+ year olds						
<b>Number of cases by age group</b>						
Annual live births			0			
All age groups						
<1 year olds						
1-4 year olds						
5-14 year olds						
15-44 year olds						
45+ year olds						
<b>% cases by level of impairment</b>						
No or minor disability			0.0			
Moderate disability*			50.0			
Severe disability*			50.0			
<b>Mortality and morbidity</b>						
Mean life expectancy (yrs)						
No. deaths < 1yr			0			
No. deaths 1-4 yrs			0			
No. deaths < 5 yrs			0			
Infant mortality / 1000 LB			0.00			
Under-5 mortality / 1000 LB			0.00			
Years of life lost						

LB = live births; SB = stillbirths \* Moderate = 6-15% HbA present; Severe = 1-5% HbA present

**Timor-Leste****Sickle Cell Disease****SCD Epidemiology 1.2: International comparison**

Epidemiological indicator	Your chosen estimates	Comparison		
		Country	Region	World
Prevalence at birth and by age-group (/1000 people)		(Asia, Southeast)		
Live birth prevalence (LB)		0.00	0.00	2.70
Stillbirth prevalence (SB)		0.00	0.00	0.00
Total birth prevalence (LB+SB)		0.00	0.00	2.70
All age groups				
<1 year olds				
1-4 year olds				
5-14 year olds				
15-44 year olds				
45+ year olds				
Number of cases by age-group				
Annual live births		0	6	358127
All age groups			0	0
<1 year olds			0	0
1-4 year olds			0	0
5-14 year olds			0	0
15-44 year olds			0	0
45+ year olds			0	0
% cases by level of impairment				
No or minor disability		0.0	7.13	11.74
Moderate disability		50.0	50.00	50.00
Severe disability*		50.0	42.87	38.26
Mortality and morbidity				
Mean life expectancy (yrs)				
No. deaths < 1yr		0	0	168737
No. deaths 1-4 yrs		0	0	42184
No. deaths < 5 yrs		0	0	210921
Infant mortality / 1000 LB		0.00	0.00	1.27
Under-5 mortality / 1000 LB		0.00	0.00	1.59
Years of life lost				

LB = live births; SB = stillbirths \* Moderate = 6-15% HbA present; Severe = 1-5% HbA present

**Timor-Leste****Sickle Cell Disease****SCD Epidemiology 2.1: Data on affected pregnancies: Research studies**

Study author, year, site	Sample size	Study quality and representativeness	Main findings

Based on the studies listed above (or in section SCD-E2.1 of the Tool), enter the best estimates for the prevalence of affected births and still births in the country, and a range of values to reflect uncertainty or within-country variation.

If studies are not representative of the national population you may need to weight your data (see the Guide for explanation on weighting and help with the calculations).

Estimates for the total country/territory	Number of affected live births	LB prevalence / 1000 TB	Comments
Best estimate			
Lower estimate			
Higher estimate			
Estimates for the total country/territory	Number of affected stillbirths	SB prevalence / 1000 TB	Comments
Best estimate			
Lower estimate			
Higher estimate			

TB = total births (live births + stillbirths)



**Timor-Leste****Sickle Cell Disease****SCD Epidemiology 2.2: Data on affected pregnancies: Surveillance**

Based on surveillance data, enter the best estimates for the prevalence of the condition in live births and stillbirths. Give a range of values to reflect uncertainty and within-country variation, and use comments for information on data quality, uncertainty and representativeness.

If studies are not representative of the national population you may need to weight your data (see the Guide for explanation on weighting and help with the calculations).

Estimates for the total country/territory	Number of affected live births	Birth prevalence / 1000 TB	Comments
Best estimate			
Lower estimate			
Higher estimate			

Estimates for the total country/territory	Number of affected stillbirths	Stillbirth prevalence / 1000 TB	Comments
Best estimate			
Lower estimate			
Higher estimate			

TB = total births (live births + stillbirths)

**Timor-Leste****Sickle Cell Disease****SCD Epidemiology 2.3: Data on affected pregnancies: Other sources**

	Source 1:	Source 2:	Notes
Enter year and source of data – use last year with information available.			
<b>Basic Numbers</b>			
Number of affected live births / year, from data source			
Total number of live births / year, from data source			
Number of affected still births / year, from data source			
Total number of stillbirths / year, from data source			
Total number of affected births / year (live and still)	0	0	Number of affected live births + Number of affected still births
Total number of births / year, from data source	0	0	Total number of live births + Total number of still births
Total number of women aged 15-44			
<b>Live birth prevalence: recorded and estimated</b>			
Recorded live birth prevalence (affected recorded live births / 1000 recorded total births)	#DIV/0!	#DIV/0!	
Estimated completeness of recording: what proportion of true affected live births in your data source were recorded?			Range: 0 to 1
Estimated coverage of recorded live births (number of recorded live births / total live births in country or territory)			Range: 0 to 1
Estimated live birth prevalence (recorded prevalence / completeness)	#DIV/0!	#DIV/0!	
Estimated true number of affected live births in data source (number of recorded affected live births / completeness)	#DIV/0!	#DIV/0!	
Estimated number of affected live births in total population (number of affected live births from data source / (coverage x completeness))	#DIV/0!	#DIV/0!	
<b>Stillbirth prevalence: recorded and estimated</b>			
Recorded stillbirth prevalence (affected recorded still births / 1000 recorded total births)	#DIV/0!	#DIV/0!	
Estimated completeness of recording: what proportion of true affected stillbirths in your data source were recorded?			Range: 0 to 1
Estimated coverage of recorded stillbirths (number of recorded still births / total still births in country or territory)			Range: 0 to 1
Estimated stillbirth prevalence (recorded prevalence / completeness)	#DIV/0!	#DIV/0!	
Estimated true number of affected stillbirths in data source (number of recorded affected still births / completeness)	#DIV/0!	#DIV/0!	
Estimated number of affected stillbirths in total population (number of affected still births from data source / (coverage x completeness))	#DIV/0!	#DIV/0!	

**Based on the sources above**, enter the best prevalence estimates for your population, and a range of values to reflect uncertainty of estimates and within country variation.

If studies are not representative of the national population you may need to weight your data (see the Guide for explanation on weighting and help with the calculations).

Estimates for the whole country/territory	Number of affected live births	LB prevalence / 1000 TB
Best estimate		
Lower estimate		
Higher estimate		
Estimates for the whole country/territory	Number of affected still births	SB prevalence / 1000 TB
Best estimate		
Lower estimate		
Higher estimate		

TB = total births (live births + stillbirths)

**Timor-Leste****Sickle Cell Disease****SCD Epidemiology 2.4: Summary of affected pregnancies**

Indicator	Your estimates	Range	PHGDB minimum estimates	Chosen estimates	Range	Source
Number of annual affected <b>live births</b>			0			
Annual birth prevalence / 1000 TB			0.00			
Number of annual affected <b>still births</b>			0			
Annual Stillbirth prevalence / 1000 TB			0.00			

If there are specific sub-types of condition, you can repeat this exercise below. However, you should consider (a) whether sub-types would have different implications for advocacy, and (b) whether a sub-type might require a full, specific needs assessment.

TB = total births (live births + stillbirths)

**Timor-Leste****Sickle Cell Disease****SCD Epidemiology 2.5: Sub-population variation in affected pregnancies**

If the birth prevalence rates vary by population sub-group (e.g. geographically or by another factor), indicate any population groups with different prevalence estimates from the whole population and describe reasons for variation. If a group is substantially different from the general population, you may wish to conduct a needs assessment for that group alone.

Population sub-group	Number of affected live births	LB prevalence / 1000 TB	Reason for variation

Population sub-group	Number of affected stillbirths	SB prevalence / 1000 TB	Reason for variation

TB = total births (live births + stillbirths)

**Timor-Leste****Sickle Cell Disease****SCD Epidemiology 3.1: Mortality data: Research studies**

Source, year, site	Sample size	Age group	Study quality and representativeness	Main findings

Based on the studies above, enter the best estimates for the specific mortality by age-group e.g. infant, under-5s, etc., as appropriate, and a range of values to reflect uncertainty of estimates and within-country variation.

If studies are not representative of the national population you may need to weight your data (see the Guide for explanation on weighting and help with the calculations).

Mortality estimates	Number of deaths	Ratio (deaths / 1000 LB)	Comments
<b>Neonatal group (&lt;28 days)</b>			
Best estimate			
Lower estimate			
Higher estimate			
<b>Infant group (&lt;1 year)</b>			
Best estimate			
Lower estimate			
Higher estimate			
<b>Under-5 group (&lt;5 years)</b>			
Best estimate			
Lower estimate			
Higher estimate			
<b>Other age group:</b>			
Best estimate			
Lower estimate			
Higher estimate			

LB = live births

**Timor-Leste****Sickle Cell Disease****SCD Epidemiology 3.2: Mortality data: Vital registration data**

Fill in the blank cells based on your vital registration data.	
Enter year and source of data	
<b>Registered data</b>	
Total registered live births	
Registered condition-specific neonatal deaths (first 28 days of life)	
Registered condition-specific infant deaths (first year of life)	
Registered condition-specific under-5 deaths (first 5 years of life)	
Registered condition-specific neonatal mortality ratio (condition-specific neonatal deaths / (Total registered live births / 1000))	#DIV/0!
Registered condition-specific infant mortality ((condition-specific infant deaths / (Total registered live births / 1000))	#DIV/0!
Registered condition-specific under-5 mortality (condition-specific under-5 deaths / (Total registered live births / 1000))	#DIV/0!

**Adjustment for under-ascertainment of cause of death and sub-registration of deaths:** Enter estimates in the highlighted cells. It is not always possible to adjust the estimates, in which case you may give the value '1', accepting that the estimates in these cases will usually be biased towards low values. (Or you may move to the next section.) It is assumed that under-ascertainment is stable across age-groups; if ascertainment varies by age-group, you could use separate estimates for each age group.

Estimated completeness of recording: what proportion of deaths in affected persons were registered as such?		Range: 0 to 1
Population coverage: what proportion of the total country/territory population is covered by the vital registration?		
Death ascertainment (population coverage x completeness)	0	
<b>Estimated values for the total country/ territory population</b>		
Estimated number of live births in total population (Total registered live births/population coverage)	#DIV/0!	
Estimated number of neonatal deaths in total population (number of deaths registered in neonatal period / ascertainment)	#DIV/0!	
Estimated number of infant deaths in total population (number of deaths registered in first year of life / ascertainment)	#DIV/0!	
Estimated number of under-5 deaths in total population (number of deaths registered in under-5s / ascertainment)	#DIV/0!	
Estimated neonatal mortality ratio (estimated neonatal deaths / 1000 live births)	#DIV/0!	
Estimated infant mortality ratio (estimated infant deaths / 1000 live births)	#DIV/0!	
Estimated under-5 mortality ratio (estimated under-5 deaths / 1000 live births)	#DIV/0!	

**Timor-Leste****Sickle Cell Disease****SCD Epidemiology 3.3: Mortality data: Other sources**

Source, year, site	Sample size	Age group	Data quality and representativeness	Main findings

Based on data from the sources above, enter estimates for the disease-specific deaths and mortality rates in your population.

If studies are not representative of the national population you may need to weight your data (see the Guide for explanation on weighting and help with the calculations).

	Neonatal mortality		Infant mortality		Under-5 mortality	
Estimates for the total country/territory	Value	Ratio/1000 LB	Value	Ratio/1000 LB	Value	Ratio/1000 LB
Best estimate						
Lower estimate						
Higher estimate						



**Timor-Leste****Sickle Cell Disease****SCD Epidemiology 3.4: Summary mortality estimates**

Indicator	Your estimates	Range	PHGDB minimum estimates	Chosen estimates	Range	Source
Year of data collection						
Number of annual deaths in affected persons						
Number of annual live births (in 1000s)			45			
Number of annual affected neonatal deaths			0			
Number of affected neonatal deaths / 1000 LB			0.00			
Number of annual affected infant deaths			0			
Number of affected infant deaths / 1000 LB			0.00			
Number of annual affected under-5 deaths			0			
Number of affected under-5 deaths / 1000 LB			0.00			
Mean life expectancy at birth in affected people						
Other indicators (e.g. survival following surgical procedure, etc)						

If there are specific sub-types of condition, you can repeat this exercise (copy table and paste below). However, you should consider (a) whether sub-types would have different implications for advocacy, and (b) whether a sub-type might require a full, specific needs assessment.

**Timor-Leste****Sickle Cell Disease****SCD Epidemiology 3.5: Sub-population variation in mortality**

Age group: neonatal Population sub-group	Number of deaths in affected persons	Cause-specific, group-specific neonatal mortality ratio / 1000 LB	Reason for variation

Age group: infant Population sub-group	Number of deaths in affected persons	Cause-specific, group-specific infant mortality ratio / 1000 LB	Reason for variation

Age group: under 5 Population sub-group	Number of deaths in affected persons	Cause-specific, group-specific under-5 mortality ratio / 1000 LB	Reason for variation

Age group: ..... Population sub-group	Number of deaths in affected persons	Cause-specific, group-specific mortality ratio / 1000 population	Reason for variation

**Timor-Leste****Sickle Cell Disease****SCD Epidemiology 4.1: Population prevalence: Research studies**

Study, year, site	Sample size	Study quality and representativeness	Main findings

Based on the studies above, enter the best estimates for population prevalence, and a range of values to reflect uncertainty of estimates and within-country variation.

If studies are not representative of the national population you may need to weight your data (see the Guide for explanation on weighting and help with the calculations).

	Prevalence / 1000 persons	Range	Comments
Best estimate			
Lower estimate			
Higher estimate			

If there are specific sub-types of condition, you can repeat this exercise (copy table and paste below). However, you should consider (a) whether sub-types would have different implications for advocacy, and (b) whether a sub-type might require a full, specific needs assessment.

**Timor-Leste****Sickle Cell Disease****SCD Epidemiology 4.2: Population prevalence: Other sources**

Source, year, site	Sample size	Data quality and representativeness	Main findings

Based on data from the sources above, enter estimates for the disease-specific deaths and mortality rates in your population.

If studies are not representative of the national population you may need to weight your data (see the Guide for explanation on weighting and help with the calculations).

	Prevalence / 1000 persons	Range	Comments
Best estimate			
Lower estimate			
Higher estimate			

If there are specific sub-types of condition, you can repeat this exercise (copy table and paste below). However, you should consider (a) whether sub-types would have different implications for advocacy, and (b) whether a sub-type might require a full, specific needs assessment.

**Timor-Leste****Sickle Cell Disease****SCD Epidemiology 4.3: Summary of population prevalence**

Source of estimates	Estimated total population number of affected persons	Range	Estimated total population prevalence / 1000 persons	Range
1				
2				
3				
4				
5				
PHGDB				
<b>Chosen estimates</b>				

If there are specific sub-types of condition, you can repeat this exercise (copy table and paste below). However, you should consider (a) whether sub-types would have different implications for advocacy, and (b) whether a sub-type might require a full, specific needs assessment.

**Timor-Leste****Sickle Cell Disease****SCD Epidemiology 4.4: Sub-population prevalence variation**

Population sub-group	Number of affected people	Total number of people in population sub-group	Population prevalence per 1000 people	Reason for variation
			#DIV/0!	
			#DIV/0!	
			#DIV/0!	
			#DIV/0!	

If there are specific sub-types of condition, you can repeat this exercise (copy table and paste below). However, you should consider (a) whether sub-types would have different implications for advocacy, and (b) whether a sub-type might require a full, specific needs assessment.

Formula in column D: Number of affected people/ (Total number of people in population subgroup/1000)

**Timor-Leste****Sickle Cell Disease****SCD Intervention 1: 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****Sickle Cell Disease****SCD Needs Assessment 1: Quantitative baseline****Table SCD-NA1a Burden of Sickle Cell Disease in pregnancy, at birth and at population level**

Indicator	Chosen estimates			Notes
	Number (n)	n/1000 TB	Range of prevalence (/1000 TB)	
Annual affected live births (LB)	0	0	0	Drawn from sheet E2.4
Annual affected stillbirths (SB)	0	0	0	Drawn from sheet E2.4
Annual affected births (LB+SB)	0	0		Drawn from sheet E2.4
Annual affected persons (all age groups)	0	0	0	Drawn from sheet E1.1

**Table SCD-NA1b Sickle Cell Disease mortality indicators**

Indicator	Chosen estimates			Notes
	Number (n)	n/1000 LB	Range of prevalence (/1000 TB)	
Annual overall mortality	0			Drawn from sheet E3.4
Annual neonatal mortality	0	0	0	Drawn from sheet E3.4
Annual infant mortality	0	0	0	Drawn from sheet E3.4
Annual under-5 mortality	0	0	0	Drawn from sheet E3.4
Mean life expectancy at birth among affected people	0		0	Drawn from sheet E3.4

TB = total births (live births + stillbirths)



**Timor-Leste****Sickle Cell Disease****SCD Needs Assessment 3: Quantitative assessment of interventions**

<b>Table SCD-NA3a</b>	<b>Estimated prevalence in the absence of interventions for Sickle Cell Disease</b>	
Indicator	Number (n)	Prevalence (n/1000)
Potential live births		
Potential still births		

<b>Table SCD-NA3b</b>	<b>Current situation in relation to interventions before birth</b>		
Intervention	Coverage (%)	Cases averted (n)	Cases averted/1000 LB
Effect of family planning, education			
Effect of population carrier screening			
Effect of preconception screening			
Effect of prenatal screening			
Effect of prenatal diagnosis			
Overall effect			

<b>Table SCD-NA3c</b>	<b>Target situation in relation to interventions before birth</b>		
Intervention	Coverage (%)	Cases averted (n)	Cases averted/1000 LB
Effect of family planning, education			
Effect of population carrier screening			
Effect of preconception screening			
Effect of prenatal screening			
Effect of prenatal diagnosis			
Overall effect			

<b>Table SCD-NA3d</b>	<b>Current situation in relation to interventions after birth</b>		
Intervention	Coverage (%)	Cases managed (n)	Cases managed/1000 LB
Effect of newborn diagnosis			
Effect of blood transfusion			
Effect of infection prevention			
Effect of iron chelation			
Effect of social care and support			
Overall effect			

<b>Table SCD-NA3e</b>	<b>Target situation in relation to interventions after birth</b>		
Intervention	Coverage (%)	Cases managed (n)	Cases managed/1000 LB
Effect of newborn diagnosis			
Effect of blood transfusion			
Effect of infection prevention			
Effect of iron chelation			
Effect of social care and support			
Overall effect			

<b>Table SCD-NA3f</b>	<b>Current and desired outcomes</b>			
	<b>Current situation</b>		<b>Target situation</b>	
Indicator	Annual number (n)	Incidence (n/1000)	Annual number (n)	Incidence (n/1000)
<b>Estimated affected pregnancies</b>				
Live births (LB)	0	0		
Still births (SB)	0	0		
All births (LB+SB)	0	0		
<b>Estimated population prevalence</b>				
All age groups				
<b>Estimated mortality</b>				
Neonatal deaths	0	0		
Infant deaths	0	0		
Under-5 deaths	0	0		