PHG Needs Assessment Calculator
Democratic Republic of The Congo
Thalassaemias

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Democratic Republic of The Congo
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	162324	161268	323592			0			0
5-9 years	143834	144750	288584			0			0
10-14 years	123671	123947	247618			0			0
15-19 years	104895	111131	216026			0			0
20-24 years	82696	89286	171982			0			0
25-29 years	66373	71330	137703			0			0
30-34 years	47874	53111	100985			0			0
35-39 years	40114	44821	84935			0			0
40-44 years	34108	35685	69793			0			0
45-49 years	32497	36058	68555			0			0
50-54 years	25558	30836	56394			0			0
55-59 years	21730	26871	48601			0			0
60-64 years	16464	22735	39199			0			0
65+ years	28068	33749	61817			0			0
Total	0	0	1924332	0	0	0	0	0	0
Female population aged 15-44 years		0			-			-	
Data year		1985 reported in 1986							
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	50	Unicef, 2007				
Still birth rate (SB): Still births (SB) / year / 1000 total births	29	WHO, 2009				
Total births in 1000s (LB+SB) per year	3118	Unicef, 2007				
Infant mortality rate: infant deaths / 1000 LB / year	112	UNICEF (2011), 2010				
Under-5 mortality rate: U5 deaths / 1000 LB / year	170	UNICEF (2011), 2010				
Percentage births in women >35 years						
Life expectancy at birth (yrs)	49	WHO, 2009				
% of marriages consanguineous						

Maternal health	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Prenatal visits – at least 1 visit (%)	87	WHO, 2010				
Prenatal visits – at least 4 visits (%)	47	WHO, 2007				
Births attended by skilled health personnel (%)	74	WHO, 2010				
Contraception prevalence rate (%)	20.6	WHO, 2007				
Unmet need for family planning (%)	24.4	WHO, 2007				
Total fertility rate	5.9	WHO, 2009				
% home births						
% births at health care services						
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. $)	280	WHO, 2008				
% population living on < US$1 per day	59.2	WHO, 2006				
Birth registration coverage (%)	31	WHO, 2007				
Death registration coverage (%)						

LB = live births
PPP = purchasing power parity
SBA = skilled birth attendant

Democratic Republic of The Congo
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. $)	7	WHO, 2009				
Total expenditure on health as percentage of GDP	2.0	WHO, 2009				
Per capita government expenditure on health (PPP int. $)	2	WHO, 2009				
External resources for health as percentage of total expenditure on health	118.8	WHO, 2009				
General government expenditure on health as percentage of total expenditure on health	23.9	WHO, 2009				
Out-of-pocket expenditure as percentage of private expenditure on health	0	WHO, 2009				
Private expenditure on health as percentage of total expenditure on health	76.1	WHO, 2009				
General government expenditure on health as percentage of total government expenditure	1.7	WHO, 2009				

Health Workforce	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Number of nursing and midwifery personnel	28789	WHO, 2004				
Nursing and midwifery personnel density (per 10,000 population)	5.3	WHO, 2004				
Number of physicians	5827	WHO, 2004				
Physician density (per 10,000 population)	1.1	WHO, 2004				
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 facillities for safe terminations of pregnancies for fetal defects						

PPP = purchasing power parity
GDP = gross domestic product
SBA = skilled birth attendant
CD = congenital disorders

Democratic Republic of The Congo
Thalassaemias
THAL Epidemiology 1.1: Country epidemiology

Epidemiological indicator	Your estimates	Range	PHGDB minimum estimates	Chosen estimates	Range	Source
Year of estimate						
Prevalence at birth and by age-group (/1000)						
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						
Number of cases by age group						
Annual live births			1			
All age groups						
<1 year olds						
1-4 year olds						
5-14 year olds						
15-44 year olds						
45+ year olds						
No. of cases by level of impairment						
No or minor disability						
Moderate disability*						
Severe disability*						
Mortality and morbidity						
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 = thalassaemia intermedia; Severe =thalassaemia major

Democratic Republic of The Congo
Thalassaemias
THAL Epidemiology 1.2: International comparison

Epidemiological indicator	Your chosen estimates	Comparison		
		Country	Region	World
Prevalence at birth and by age-group (/1000 people)			**(Sub-Saharan Africa, Central)**	
Live birth prevalence (LB)		0.00	0.00	0.39
Stillbirth prevalence (SB)		0.00	0.00	0.00
Total birth prevalence (LB+SB)		0.00	0.00	0.39
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		1	1	52043
All age groups				
<1 year olds				
1-4 year olds				
5-14 year olds				
15-44 year olds				
45+ year olds				
No. cases by level of impairment				
No or minor disability				
Moderate disability*				
Severe disability*				
Mortality and morbidity				
Mean life expectancy (yrs)				
No. deaths < 1yr		0	0	3442
No. deaths 1-4 yrs		0	0	12640
No. deaths < 5 yrs		0	0	16082
Infant mortality / 1000 LB		0.00	0.00	0.03
Under-5 mortality / 1000 LB		0.00	0.00	0.12
Years of life lost				

LB = live births; SB = stillbirths * Moderate = thalassaemia intermedia; Severe =thalassaemia major

Democratic Republic of The Congo

Thalassaemias

THAL 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 THAL-E2.1 of the Tool), enter the best estimates for the prevalence of affected births and terminations 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			
Estimates for the total country/territory	**Number of terminations of pregnancy due to condition**	**ToP / 1000 TB**	**Comments**
Best estimate			
Lower estimate			
Higher estimate			

TB = total births (live births + stillbirths); ToP = termination of pregnancy

Democratic Republic of The Congo
Thalassaemias
THAL 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, stillbirths and pregnancy terminations in the country. 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			

Estimates for the total country/territory	Number of ToP due to condition	ToP / 1000 TB	Comments
Best estimate			
Lower estimate			
Higher estimate			

TB = total births (live births + stillbirths); ToP = termination of pregnancy

Democratic Republic of The Congo
Thalassaemias
THAL 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.			
Basic Numbers			
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			
Number of ToP for affected fetus / 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 ToP / year, from data source			
Total number of women aged 15-44			
Live birth prevalence: recorded and estimated			
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!	
Stillbirth prevalence: recorded and estimated			
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!	

ToP prevalence: recorded and estimated			
Recorded ToP prevalence (ToP in affected fetuses / 1000 women aged 15-44)	#DIV/0!	#DIV/0!	
Estimated completeness of recording: what proportion of true affected pregnancy terminations in your data source were recorded?			Range: 0 to 1
Estimated coverage of recorded ToP (number of recorded ToP / total ToP in country or territory)			Range: 0 to 1
Estimated ToP prevalence (recorded prevalence / estimated completeness)	#DIV/0!	#DIV/0!	
Estimated true number of ToP in data source (number of recorded ToP / completeness)	#DIV/0!	#DIV/0!	
Estimated number of ToP in total population (number of ToP 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		
Estimates for the whole country/territory	**Number of ToP due to condition**	**ToP /1000 TB**
Best estimate		
Lower estimate		
Higher estimate		

TB = total births (live births + stillbirths); ToP = termination of pregnancy

Democratic Republic of The Congo
Thalassaemias
THAL Epidemiology 2.4: Summary of affected pregnancies

Indicator	Your estimates	Range	PHGDB minimum estimates	Chosen estimates	Range	Source
Number of annual affected **live births**			1			
Annual birth prevalence / 1000 TB			0.00			
Number of annual affected **still births**			0			
Annual Stillbirth prevalence / 1000 TB			0.00			
Number of **terminations of pregnancy** in affected fetuses /year			0			
Affected ToP / 1000 women 15-44/ year			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); ToP = termination of pregnancy

Democratic Republic of The Congo
Thalassaemias
THAL 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

Population sub-group	Number of ToP in affected pregnancies	ToP prevalence / 1000 TB	Reason for variation

TB = total births (live births + stillbirths); ToP = termination of pregnancy

Democratic Republic of The Congo
Thalassaemias
THAL 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
Neonatal group (<28 days)			
Best estimate			
Lower estimate			
Higher estimate			
Infant group (<1 year)			
Best estimate			
Lower estimate			
Higher estimate			
Under-5 group (<5 years)			
Best estimate			
Lower estimate			
Higher estimate			
Other age group:			
Best estimate			
Lower estimate			
Higher estimate			

LB = live births

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Thalassaemias
THAL 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	
Registered data	
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?		Range: 0 to 1
Death ascertainment (population coverage x completeness)	0	
Estimated values for the total country/ territory population		
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!	

Democratic Republic of The Congo
Thalassaemias
THAL 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						

Democratic Republic of The Congo
Thalassaemias
THAL 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)			2,788			
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.

Democratic Republic of The Congo
Thalassaemias
THAL 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

Democratic Republic of The Congo
Thalassaemias
THAL 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.

Democratic Republic of The Congo
Thalassaemias
THAL 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.

Democratic Republic of The Congo
Thalassaemias
THAL 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				
Chosen estimates				

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.

Democratic Republic of The Congo
Thalassaemias
THAL 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)

Democratic Republic of The Congo

Thalassaemias

THAL Intervention 1: Effect of prenatal diagnosis and pregnancy termination

Note: this makes the simplifying assumption that stillbirth is equally likely in cases that are diagnosed as in cases that are not diagnosed.

Assumption: prenatal services are equally used for cases which would lead to stillbirths and live births.

This could overestimate the impact of ToP if in fact ToP is more likely for severe cases that would result in stillbirth.

Conversely, the impact of ToP could be underestimated if screening is only available to high-income women at lower risk.
100% specificity of prenatal diagnosis assumed.

Birth prevalence: thalassaemia-affected pregnancies per 1000 TB		
Variables		
Coverage of preconception and prenatal screening and diagnosis		Range: 0 to 1
Proportion of cases diagnosed		Range: 0 to 1
Proportion of diagnosed cases ending in ToP		Range: 0 to 1
Results		
% prevalence reduction due to PND & ToP[1]	0%	
Prevalence reduction due to PND & ToP, per 1000 TB[2]	0.000	
Final prevalence: affected live births after PND & ToP, per 1000 TB[3]	0.000	

PND = prenatal diagnosis

TB = total births (live births + still births)

ToP = termination of pregnancy

[1]Coverage of PNS and diagnosis X Proportion of cases diagnosed x Proportion of cases ending in ToP

[2]% prevalence reduction due to PNS and ToP x Birth prevalence

[3]Birth prevalence – Prevalence reduction due to PNS & ToP

Democratic Republic of The Congo

Thalassaemias

THAL Intervention 2: 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 positive-screened patients referred for management		Range: 0 to 1
Effectiveness of management		Range: 0 to 1
Results		
Proportional reduction in unmanaged cases of 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).

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

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

Democratic Republic of The Congo
Thalassaemias
THAL Needs Assessment 1: Quantitative baseline

Table THAL-NA1a Burden of Thalassaemias in pregnancy, at birth and at population level

	Chosen estimates			Notes
Indicator	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 THAL-NA1b Thalassaemias mortality indicators

	Chosen estimates			Notes
Indicator	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)

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Table THAL-NA3a	**Estimated prevalence in the absence of interventions for thalassaemias**	
Indicator	Number (n)	Prevalence (n/1000)
Potential live births		
Potential still births		

Table THAL-NA3b	**Current situation in relation to interventions before birth**		
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			
Effect of termination of pregnancy			
Overall effect			

Table THAL-NA3c	**Target situation in relation to interventions before birth**		
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			
Effect of termination of pregnancy			
Overall effect			

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

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

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