#### PHG Needs Assessment Calculator Iceland Congenital Hypothyroidism

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(There is no sheet CHT-NA2.)

Please note condition specific data in this sheet relates to thyroid a/dysgenesis, plus the rare inherited thyroid disorders, as detected by neonatal screening in countries without iodine deficiency.

## Iceland 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		Yo	our estimat	es		Chosen es	timates
Age group	Male	Female	Total	Male	Female	Total	Male	Female	Total
0-4 years	11945	11305	23250			0			0
5-9 years	10860	10540	21400			0			0
10-14 years	11134	10710	21844			0			0
15-19 years	12182	11617	23799			0			0
20-24 years	11644	11350	22994			0			0
25-29 years	12358	11747	24105			0			0
30-34 years	11537	10919	22456			0			0
35-39 years	11185	10522	21707			0			0
40-44 years	10809	10604	21413			0			0
45-49 years	11147	11024	22171			0			0
50-54 years	10713	10385	21098			0			0
55-59 years	9267	8935	18202			0			0
60-64 years	7704	7418	15122			0			0
65+ years	17451	20618	38069			0			0
Total	0	0	317630	0	0	0	C	0 0	0
Female population aged 15-44 years		0			-			-	
Data year		2010 report	ed in 2011						
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	14	Unicef, 2007				
Still birth rate (SB): Still births (SB) / year / 1000 total births	2	WHO, 2009				
Total births in 1000s (LB+SB) per year	4	Unicef, 2007				
Infant mortality rate: infant deaths / 1000 LB / year	2	UNICEF				
Under-5 mortality rate: U5 deaths / 1000 LB / year	2	UNICEF				
Percentage births in women >35 years						
Life expectancy at birth (yrs)	82	WHO, 2009				
% of marriages consanguineous						

Maternal health	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Prenatal visits – at least 1 visit (%)						
Prenatal visits – at least 4 visits (%)						
Births attended by skilled health personnel (%)						
Contraception prevalence rate (%)						
Unmet need for family planning (%)						
Total fertility rate	2.1	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. \$)	25300	WHO, 2008				
% population living on < US\$1 per day						
Birth registration coverage (%)	>90	WHO, 2008				
Death registration coverage (%)	90-100	WHO, 2009				

LB = live births

PPP = purchasing power parity

SBA = skilled birth attendant

## Iceland 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. \$)	3095	WHO, 2009				
Total expenditure on health as percentage of GDP	8.2	WHO, 2009				
Per capita government expenditure on health (PPP int. \$)	2546	WHO, 2009				
External resources for health as percentage of total expenditure on health	0	WHO, 2009				
General government expenditure on health as percentage of total expenditure on health	82.3	WHO, 2009				
Out-of-pocket expenditure as percentage of private expenditure on health	90.8	WHO, 2009				
Private expenditure on health as percentage of total expenditure on health	17.7	WHO, 2009				
General government expenditure on health as percentage of total government expenditure	13.1	WHO, 2009				

Health Workforce	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Number of nursing and midwifery personnel	4976	WHO, 2008				
Nursing and midwifery personnel density (per 10,000 population)	164.8	WHO, 2008				
Number of physicians	1188	WHO, 2008				
Physician density (per 10 000 population)	39.34	WHO, 2008				
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 terminations of pregnancies for fetal defects						

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

CD = congenital disorders

## Congenital Hypothyroidism

CHT 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(/1	000)					
Live birth prevalence (LB)			0.25			
Stillbirth prevalence (SB)			0.00			
Total birth prevalence (LB+SB)			0.25			
All age groups						
<1 year olds			0.24			
1-4 year olds			0.24			
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			
1-4 year olds			4			
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)			76.0			
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						
D live births *Tesstal and effectively sured i						

LB = live births \*Treated and effectively cured, \*\*Treated with residual disability, \*\*\*Untreated disorder

Congenital Hypothyroidism

CHT Epidemiology 1.2: International comparison

	Your chosen		Comparison	
Epidemiological indicator	estimates	Country	Region	World
Prevalence at birth and by age-group (/1000 peop	ole)		(Europe, Wester	n)
Live birth prevalence (LB)		0.25	0.25	0.22
Stillbirth prevalence (SB)		0.00	0.00	0.00
Total birth prevalence (LB+SB)		0.25	0.25	0.22
All age groups				
<1 year olds		0.24		
1-4 year olds		0.24		
5-14 year olds				
15-44 year olds				
45+ year olds				
Number of cases by age-group				
Annual live births		1	1055	28651
All age groups				
<1 year olds		1	1055	24227
1-4 year olds		4	4221	61519
5-14 year olds				
15-44 year olds				
45+ year olds				
No. cases by level of impairment				
No or minimum disability				
Moderate disability				
Severe disability				
Mortality and morbidity				
Mean life expectancy (yrs)		76.0		
No. deaths < 1yr		0	0	4424
No. deaths 1-4 yrs		0	0	17695
No. deaths < 5 yrs		0	0	22118
Infant mortality / 1000 LB		0.00	0.00	0.03
Under-5 mortality / 1000 LB		0.00	0.00	0.17
Years of life lost				

LB = live births \*Treated and effectively cured, \*\*Treated with residual disability, \*\*\*Untreated disorder

#### Congenital Hypothyroidism

#### CHT 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 CHT-E2.1 of the Tool), enter the best estimates for the prevalence of affected births and stillbirths 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 still births	SB prevalence / 1000 TB	Comments
Best estimate			
Lower estimate			
Higher estimate			

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

## Iceland Congenital Hypothyroidism CHT 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 still births 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 still births	Stillbirth prevalence / 1000 TB	Comments
Best estimate			
Lower estimate			
Higher estimate			

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

# Congenital Hypothyroidism

## CHT 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			
Total number of affected births / year (live and still)	0	0	
Total number of births / year, from data source	0	0	
Total number of women aged 15-44			
Live birth prevalence: recorded and estimated			
Recorded live birth prevalence (affected recorded live births / 1000 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 still births 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 stillbirths	SB prevalence / 1000 TB
Best estimate		
Lower estimate		
Higher estimate		

TB = total births (live births + stillbirths)

### Iceland Congenital Hypothyroidism CHT 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			0.25			
Number of annual affected stillbirths			0			
Stillbirth prevalence / 1000 TB / year			0.00			

If there are specific sub-types of condition, you can repeat this exercise below. However, you should consider (a) whether subtypes 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);

## Iceland Congenital Hypothyroidism CHT 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); ToP = termination of pregnancy

#### Iceland Congenital Hypothyroidism CHT Epidemiology 3.1: Mortality data: Research studies

Source, year, site	Sample size	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			

#### Congenital Hypothyroidism

#### CHT 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 / 1000 live births in the same year)	#DIV/0!	
Registered condition-specific infant mortality (condition-specific infant deaths / 1000 live births in the same year)	#DIV/0!	
Registered condition-specific under-5 mortality (condition-specific under-5 deaths / 1000 live births in the same year)	#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

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	#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!	

### Iceland Congenital Hypothyroidism CHT Epidemiology 3.3: Mortality data: 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).

	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						

#### Iceland Congenital Hypothyroidism CHT 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			0			
Number of annual live births (in 1000s)			4			
Number of annual affected neonatal deaths			0			
Number of affected neonatal deaths / 1000 LB			0.00			
Number of annual affected infant deaths			0	1		
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			76.0			
Other indicators (e.g. survival following surgical procedure, etc)						

## Iceland Congenital Hypothyroidism CHT 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	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

Congenital Hypothyroidism

CHT 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			

Congenital Hypothyroidism

CHT Epidemiology 4.2: Population prevalence: Other sources

Source, year, site	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			

## Iceland Congenital Hypothyroidism CHT Epidemiology 4.3: Population prevalence summary

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				

## Iceland Congenital Hypothyroidism CHT 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!	

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)

## Iceland Congenital Hypothyroidism CHT Interventions 1: Effect of newborn diagnosis and treatment

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)

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## Congenital Hypothyroidism

## CHT Needs assessment 1: Quantitative baseline

# Table CHT-NA1a Burden of Congenital Hypothyroidism in pregnancy, at birth and at population level

	Chosen estimates			Notes
Indicator	• • • •		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	0	0	0	Drawn from sheet E1.1

## Table CHT-NA1b Congenital Hypothyroidism mortality indicators

	Chosen estimates			Notes
Indicator	Number (n)		Range of prevalence (/1000 LB)	
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 in	0		0	Drawn from sheet E3.4

TB = total births (live births + stillbirths)

LB = live births

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Congenital Hypothyroidism

CHT Needs assessment 3: Quantitative assessment of interventions

	Estimated prevalence in the absence of interventions for Congenital Hypothyroidism		
Indicator	Number (n) Prevalence (n/1000)		
Potential live births			
Potential still births			

Table CHT-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 iodine fortification					
Effect of iodine supplementation					
Overall effect					

Table CHT-NA3c	Target situation in relation	on to interventions before	birth
Intervention	Coverage (%)	Cases averted (n)	Cases averted/1000 LB
Effect of family planning, education			
Effect of iodine fortification			
Effect of iodine supplementation			
Overall effect			

Table CHT-NA3d	Current situation in relation to interventions after birth				
Intervention	Coverage (%)	Cases managed (n)	Cases managed/1000 LB		
Effect of newborn screening					
Effect of newborn diagnosis					
Treatment services					
Overall effect					

Table CHT-NA3e	Target situation in	Target situation in relation to interventions after birth			
Intervention	Coverage (%)	Cases managed (n)	Cases managed/1000 LB		
Effect of newborn screening					
Effect of newborn diagnosis					
Treatment services					
Overall effect					

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Table CHT-NA3f	Current and desired outcomes			
	Current situation		Target situation	
Indicator	Annual number (n)	Prevalence (n/1000)	Annual number (n)	Prevalence (n/1000)
Estimated affected pregnancies				-
Live births (LB)	0	0		
Stillbirths (SB)	0	0		
Total births (LB+SB)	0	0		
Estimated population prevalence		^		
All age groups				
Estimated mortality / 1000 live birth	S	^		
Neonatal deaths	0	0		
Infant deaths	0	0		
Under-5 deaths	0	0		

### CHT-NA2