

PHG Needs Assessment Calculator
Iceland
Thalassaemias

Welcome to the PHG Health Needs Assessment Calculator for thalassaemias. 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 |
| THAL Epidemiology 1.1: Country epidemiology | THAL-E1.1 |
| THAL Epidemiology 1.2: International comparison | THAL-E1.2 |
| THAL Epidemiology 2.1: Data on affected pregnancies: Research studies | THAL-E2.1 |
| THAL Epidemiology 2.2: Data on affected pregnancies: Surveillance | THAL-E2.2 |
| THAL Epidemiology 2.3: Data on affected pregnancies: Other sources | THAL-E2.3 |
| THAL Epidemiology 2.4: Summary of affected pregnancies | THAL-E2.4 |
| THAL Epidemiology 2.5: Sub-population variation in affected pregnancies | THAL-E2.5 |
| THAL Epidemiology 3.1: Mortality data: Research studies | THAL-E3.1 |
| THAL Epidemiology 3.2: Mortality data: Vital registration data | THAL-E3.2 |
| THAL Epidemiology 3.3: Mortality data: Other sources | THAL-E3.3 |
| THAL Epidemiology 3.4: Summary mortality estimates | THAL-E3.4 |
| THAL Epidemiology 3.5: Sub-population variation in mortality | THAL-E3.5 |
| THAL Epidemiology 4.1: Population prevalence: Research studies | THAL-E4.1 |
| THAL Epidemiology 4.2: Population prevalence: Other sources | THAL-E4.2 |
| THAL Epidemiology 4.3: Summary of population prevalence | THAL-E4.3 |
| THAL Epidemiology 4.4: Sub-population prevalence variation | THAL-E4.4 |
| THAL Interventions 1: Prenatal diagnosis and pregnancy termination | THAL-Interv1 |
| THAL Interventions 2: Newborn screening and management | THAL-Interv2 |
| THAL Needs Assessment Calculator 1: Quantitative baseline | THAL-NA1 |
| THAL Needs Assessment Calculator 3: Quantitative assessment of interventions | THAL-NA3 |

(There is no sheet THAL-NA2.)

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 Age group | Estimates | | | Your estimates | | | Chosen estimates | | |
|---|-----------------------|--------|--------|----------------|--------|-------|------------------|--------|-------|
| | 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 | 0 | 0 | 0 |
| Female population aged 15-44 years | | 0 | | | - | | | - | |
| Data year | 2010 reported 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 | (2011), 2010 | | | | |
| Percentage births in women >35 years | | (2011), 2010 | | | | |
| 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 facilities for safe terminations of pregnancies for fetal defects | | | | | | |

PPP = purchasing power parity

GDP = gross domestic product

SBA = skilled birth attendant

CD = congenital disorders

Iceland

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 | | | 0 | | | |
| 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

Iceland

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) | | (Europe, Western) | | |
| Live birth prevalence (LB) | | 0.00 | 0.04 | 0.39 |
| Stillbirth prevalence (SB) | | 0.00 | 0.00 | 0.00 |
| Total birth prevalence (LB+SB) | | 0.00 | 0.04 | 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 | | 0 | 159 | 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 | 1 | 3442 |
| No. deaths 1-4 yrs | | 0 | 6 | 12640 |
| No. deaths < 5 yrs | | 0 | 6 | 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

Iceland**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

Iceland**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

Iceland

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 | 0 Number of affected live births + Number of affected still births |
| Total number of births / year, from data source | 0 | 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? | | |
| Estimated coverage of recorded ToP (number of recorded ToP / total ToP in country or territory) | | |
| 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! |

Range: 0 to 1

Range: 0 to 1

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

Iceland**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 | | | 0 | | | |
| 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

Iceland**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

Iceland**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

Iceland

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! | |

Iceland**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 | | | | | | |

Iceland**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) | | | 4 | | | |
| 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.

Iceland

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 |
|--|---|---|----------------------|
| | | | |
| | | | |
| | | | |
| | | | |

Iceland**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.

Iceland**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.

Iceland**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.

Iceland**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)

Iceland**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

¹Coverage 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

³Birth prevalence – Prevalence reduction due to PNS & ToP

Iceland**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).

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 thalassaemias X Baseline birth prevalence)

Iceland**Thalassaemias****THAL Needs Assessment 1: Quantitative baseline****Table THAL-NA1a Burden of Thalassaemias 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 THAL-NA1b Thalassaemias 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)

Iceland**Thalassaemias****THAL Needs Assessment 3: Quantitative assessment of interventions**

| 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 | | |