

**PHG Needs Assessment Calculator**  
**Netherlands**  
**Orofacial Clefts**

Welcome to the PHG Health Needs Assessment Calculator for Orofacial Clefts. The contents of this file are listed below:

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(There is no sheet OFC-NA2.)

**Netherlands****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                              | 473374                | 451507  | 924881   |                |        | 0     |                  |        | 0     |
| 5-9 years                              | 512808                | 490441  | 1003249  |                |        | 0     |                  |        | 0     |
| 10-14 years                            | 504126                | 480655  | 984781   |                |        | 0     |                  |        | 0     |
| 15-19 years                            | 519322                | 496101  | 1015423  |                |        | 0     |                  |        | 0     |
| 20-24 years                            | 511916                | 500994  | 1012910  |                |        | 0     |                  |        | 0     |
| 25-29 years                            | 503012                | 496343  | 999355   |                |        | 0     |                  |        | 0     |
| 30-34 years                            | 500713                | 498845  | 999558   |                |        | 0     |                  |        | 0     |
| 35-39 years                            | 591406                | 589543  | 1180949  |                |        | 0     |                  |        | 0     |
| 40-44 years                            | 655752                | 641028  | 1296780  |                |        | 0     |                  |        | 0     |
| 45-49 years                            | 650126                | 638431  | 1288557  |                |        | 0     |                  |        | 0     |
| 50-54 years                            | 591039                | 586328  | 1177367  |                |        | 0     |                  |        | 0     |
| 55-59 years                            | 544323                | 538521  | 1082844  |                |        | 0     |                  |        | 0     |
| 60-64 years                            | 536910                | 533097  | 1070007  |                |        | 0     |                  |        | 0     |
| 65+ years                              | 1108649               | 1429679 | 2538328  |                |        | 0     |                  |        | 0     |
| Total                                  | 0                     | 0       | 16574989 | 0              | 0      | 0     | 0                | 0      | 0     |
| Female population aged 15-44 years     |                       | 0       |          |                | -      |       |                  | -      |       |
| Data year                              | 2010 reported in 2010 |         |          |                |        |       |                  |        |       |
| Source, Year                           | UN 2011               |         |          |                |        |       |                  |        |       |

**Ethnicity.** Please enter data for the main ethnic groups if you are working with a population that is different from that of the country.

| Ethnic group | Number | % population |
|--------------|--------|--------------|
|              |        |              |
|              |        |              |
|              |        |              |

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| <b>Fertility and mortality</b>                                      | <b>Estimate</b> | <b>Source, Year</b> | <b>Your estimate</b> | <b>Source, Year</b> | <b>Chosen estimate</b> | <b>Source, Year</b> |
|---|-----------------|---------------------|----------------------|---------------------|------------------------|---------------------|
| Crude birth rate: live births (LB) / year / 1000 population         | 11              | Unicef, 2007        |                      |                     |                        |                     |
| Still birth rate (SB): Still births (SB) / year / 1000 total births | 3               | WHO, 2009           |                      |                     |                        |                     |
| Total births in 1000s (LB+SB) per year                              | 184             | Unicef, 2007        |                      |                     |                        |                     |
| Infant mortality rate: infant deaths / 1000 LB / year               | 4               | UNICEF              |                      |                     |                        |                     |
| Under-5 mortality rate: U5 deaths / 1000 LB / year                  | 4               | UNICEF              |                      |                     |                        |                     |
| Percentage births in women >35 years                                |                 |                     |                      |                     |                        |                     |
| Life expectancy at birth (yrs)                                      | 81              | WHO, 2009           |                      |                     |                        |                     |
| % of marriages consanguineous                                       |                 |                     |                      |                     |                        |                     |

| <b>Maternal health</b>                                 | <b>Estimate</b> | <b>Source, Year</b> | <b>Your estimate</b> | <b>Source, Year</b> | <b>Chosen estimate</b> | <b>Source, Year</b> |
|--|-----------------|---------------------|----------------------|---------------------|------------------------|---------------------|
| Prenatal visits – at least 1 visit (%)                 |                 |                     |                      |                     |                        |                     |
| Prenatal visits – at least 4 visits (%)                |                 |                     |                      |                     |                        |                     |
| Births attended by skilled health personnel (%)        | 100             | WHO, 2007           |                      |                     |                        |                     |
| Contraception prevalence rate (%)                      | 69.0            | WHO, 2008           |                      |                     |                        |                     |
| Unmet need for family planning (%)                     |                 |                     |                      |                     |                        |                     |
| Total fertility rate                                   | 1.7             | WHO, 2009           |                      |                     |                        |                     |
| % home births  |                 |                     |                      |                     |                        |                     |
| % births at health care services                       |                 |                     |                      |                     |                        |                     |
| <b>Newborn health</b>                                  | <b>Estimate</b> | <b>Source, Year</b> | <b>Your estimate</b> | <b>Source, Year</b> | <b>Chosen estimate</b> | <b>Source, Year</b> |
| Number of neonatal examinations by SBA / trained staff |                 |                     |                      |                     |                        |                     |
| % neonatal examinations by SBA/ trained staff          |                 |                     |                      |                     |                        |                     |

| <b>Socio-economic indicators</b>               | <b>Estimate</b> | <b>Source, Year</b> | <b>Your estimate</b> | <b>Source, Year</b> | <b>Chosen estimate</b> | <b>Source, Year</b> |
|--|-----------------|---------------------|----------------------|---------------------|------------------------|---------------------|
| Gross national income per capita (PPP int. \$) | 40620           | 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

**Netherlands****Shared Data****Health Services Data**

**Please read first!** If you have already completed a needs assessment for a different topic in this country, you will be able to copy the Health Services information from that Calculator into here. The information should be the same.

This section provides health-service-related information for your country.

**By default, the Toolkit contains information at the national level.**

**If you would like to use a different population, then replace country information with that of your specific population of interest.**

| <b>Health Expenditure</b>  | <b>Estimate</b> | <b>Source, Year</b> | <b>Your estimate</b> | <b>Source, Year</b> | <b>Chosen estimate</b> | <b>Source, Year</b> |
|--|-----------------|---------------------|----------------------|---------------------|------------------------|---------------------|
| Per capita total expenditure on health (PPP int. \$)                                   | 4389            | WHO, 2009           |                      |                     |                        |                     |
| Total expenditure on health as percentage of GDP                                       | 10.8            | WHO, 2009           |                      |                     |                        |                     |
| Per capita government expenditure on health (PPP int. \$)                              | 3390            | 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  | 77.3            | WHO, 2009           |                      |                     |                        |                     |
| Out-of-pocket expenditure as percentage of private expenditure on health               | 37.7            | WHO, 2009           |                      |                     |                        |                     |
| Private expenditure on health as percentage of total expenditure on health             | 15.2            | WHO, 2009           |                      |                     |                        |                     |
| General government expenditure on health as percentage of total government expenditure | 16.2            | WHO, 2009           |                      |                     |                        |                     |

| <b>Health Workforce</b>   | <b>Estimate</b> | <b>Source, Year</b> | <b>Your estimate</b> | <b>Source, Year</b> | <b>Chosen estimate</b> | <b>Source, Year</b> |
|---|-----------------|---------------------|----------------------|---------------------|------------------------|---------------------|
| Number of nursing and midwifery personnel                       | 2444            | WHO, 2008           |                      |                     |                        |                     |
| Nursing and midwifery personnel density (per 10,000 population) | 1.5             | WHO, 2008           |                      |                     |                        |                     |
| Number of physicians  | 64417           | WHO, 2007           |                      |                     |                        |                     |
| Physician density (per 10 000 population)                       | 39.21           | WHO, 2007           |                      |                     |                        |                     |
| 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 terminations of pregnancies for fetal defects |          |              |               |              |                 |              |

PPP = purchasing power parity

GDP = gross domestic product

SBA = skilled birth attendant

CD = congenital disorders

## Netherlands

## Orofacial Clefts

## OFC Epidemiology 1.1: Country epidemiology

| Epidemiological indicator                          | Your estimates | Range | PHGDB minimum estimates | Chosen estimates | Range | Source |
|--|----------------|-------|-------------------------|------------------|-------|--------|
| Year of estimate                                   |                |       |                         |                  |       |        |
| <b>Prevalence at birth and by age-group(/1000)</b> |                |       |                         |                  |       |        |
| Live birth prevalence (LB)                         |                |       | 2.18                    |                  |       |        |
| Stillbirth prevalence (SB)                         |                |       | 0.00                    |                  |       |        |
| Total birth prevalence (LB+SB)                     |                |       | 2.18                    |                  |       |        |
| All age groups                                     |                |       | 0.91                    |                  |       |        |
| <1 year olds                                       |                |       | 2.00                    |                  |       |        |
| 1-4 year olds                                      |                |       | 2.00                    |                  |       |        |
| 5-14 year olds                                     |                |       | 0.98                    |                  |       |        |
| 15-44 year olds                                    |                |       | 0.96                    |                  |       |        |
| 45+ year olds                                      |                |       | 0.66                    |                  |       |        |
| <b>Number of cases by age group</b>                |                |       |                         |                  |       |        |
| Annual live births                                 |                |       | 414                     |                  |       |        |
| All age groups                                     |                |       | 14,739                  |                  |       |        |
| <1 year olds                                       |                |       | 405                     |                  |       |        |
| 1-4 year olds                                      |                |       | 1,620                   |                  |       |        |
| 5-14 year olds                                     |                |       | 1,957                   |                  |       |        |
| 15-44 year olds                                    |                |       | 6,468                   |                  |       |        |
| 45+ year olds                                      |                |       | 4,289                   |                  |       |        |
| <b>No. of cases by level of impairment</b>         |                |       |                         |                  |       |        |
| No or minor disability*                            |                |       | 12,528                  |                  |       |        |
| Moderate disability**                              |                |       | 2,211                   |                  |       |        |
| Severe disability***                               |                |       | 147,075                 |                  |       |        |
| <b>Mortality and morbidity</b>                     |                |       |                         |                  |       |        |
| Mean life expectancy (yrs)                         |                |       | 73.0                    |                  |       |        |
| No. deaths < 1yr                                   |                |       | 9                       |                  |       |        |
| No. deaths 1-4 yrs                                 |                |       | 0                       |                  |       |        |
| No. deaths < 5 yrs                                 |                |       | 9                       |                  |       |        |
| Infant mortality / 1000 LB                         |                |       | 0.05                    |                  |       |        |
| Under-5 mortality / 1000 LB                        |                |       | 0.05                    |                  |       |        |
| Years of life lost                                 |                |       |                         |                  |       |        |

LB = live births \*Repaired OFC, effective cure, \*\* Repaired OFC, residual problems, \*\*\*Unrepaired OFC (see background chapter)

## Netherlands

## Orofacial Clefts

## OFC Epidemiology 1.2: International comparison

|   | Your chosen estimates | Comparison        |         |           |
|---|-----------------------|-------------------|---------|-----------|
| Epidemiological indicator                           |                       | Country           | Region  | World     |
| Prevalence at birth and by age-group (/1000 people) |                       | (Europe, Western) |         |           |
| Live birth prevalence (LB)                          |                       | 2.18              | 1.58    | 1.19      |
| Stillbirth prevalence (SB)                          |                       | 0.00              | 0.03    | 0.02      |
| Total birth prevalence (LB+SB)                      |                       | 2.18              | 1.61    | 1.22      |
| All age groups                                      |                       | 0.91              |         |           |
| <1 year olds  |                       | 2.00              |         |           |
| 1-4 year olds                                       |                       | 2.00              |         |           |
| 5-14 year olds                                      |                       | 0.98              |         |           |
| 15-44 year olds                                     |                       | 0.96              |         |           |
| 45+ year olds                                       |                       | 0.66              |         |           |
| Number of cases by age-group                        |                       |                   |         |           |
| Annual live births                                  |                       | 414               | 6,681   | 156,935   |
| All age groups                                      |                       | 14,739            | 538,630 | 3,872,892 |
| <1 year olds  |                       | 405               |         |           |
| 1-4 year olds                                       |                       | 1,620             | 34,016  | 486,788   |
| 5-14 year olds                                      |                       | 1,957             | 72,141  | 937,005   |
| 15-44 year olds                                     |                       | 6,468             | 259,807 | 1,826,259 |
| 45+ year olds                                       |                       | 4,289             | 172,666 | 622,840   |
| No. cases by level of impairment                    |                       |                   |         |           |
| No or minimum disability*                           |                       | 12,528            | 457,835 | 2,927,757 |
| Moderate disability**                               |                       | 2,211             | 80,794  | 631,750   |
| Severe disability***                                |                       | 147,075           | 0       | 313,385   |
| Mortality and morbidity                             |                       |                   |         |           |
| Mean life expectancy (yrs)                          |                       | 73.0              |         |           |
| No. deaths < 1yr                                    |                       | 9                 | 147     | 47,843    |
| No. deaths 1-4 yrs                                  |                       | 0                 | 0       | 4,837     |
| No. deaths < 5 yrs                                  |                       | 9                 | 147     | 52,680    |
| Infant mortality / 1000 LB                          |                       | 0.05              | 0.03    | 0.36      |
| Under-5 mortality / 1000 LB                         |                       | 0.05              | 0.03    | 0.40      |
| Years of life lost                                  |                       |                   |         |           |

LB = live births \*Repaired OFC, effective cure, \*\* Repaired OFC, residual problems, \*\*\*Unrepaired OFC (see background chapter)

**Netherlands****Orofacial Clefts****OFC 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 OFC-E2.1 of the Tool), enter the best estimates for the prevalence of affected births and still births in the country, and a range of values to reflect uncertainty or within-country variation.

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

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

TB = total births (live births + stillbirths)



**Netherlands****Orofacial Clefts****OFC Epidemiology 2.2: Data on affected pregnancies: Surveillance**

Based on surveillance data, enter the best estimates for the prevalence of the condition in live births and stillbirths 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                           |                                 |                                 |          |

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

**Netherlands****Orofacial Clefts****OFC Epidemiology 2.3: Data on affected pregnancies: Other sources**

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

| <b>Estimates for the whole country/territory</b> | <b>Number of affected live births</b> | <b>LB prevalence / 1000 TB</b> |
|--|---------------------------------------|--------------------------------|
| Best estimate                                    |                                       |                                |
| Lower estimate                                   |                                       |                                |
| Higher estimate                                  |                                       |                                |
| <b>Estimates for the whole country/territory</b> | <b>Number of affected stillbirths</b> | <b>SB prevalence / 1000 TB</b> |
| Best estimate                                    |                                       |                                |
| Lower estimate                                   |                                       |                                |
| Higher estimate                                  |                                       |                                |

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

**Netherlands****Orofacial Clefts****OFC Epidemiology 2.4: Summary of affected pregnancies**

| Indicator                                    | Your estimates | Range | PHGDB minimum estimates | Chosen estimates | Range | Source |
|--|----------------|-------|-------------------------|------------------|-------|--------|
| Number of annual affected <b>live births</b> |                |       | 414                     |                  |       |        |
| Annual birth prevalence / 1000 TB            |                |       | 2.18                    |                  |       |        |
| Number of annual affected <b>stillbirths</b> |                |       | 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 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

**Netherlands****Orofacial Clefts****OFC 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)

**Netherlands****Orofacial Clefts****OFC Epidemiology 3.1: Mortality data: Research studies**

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

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

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

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

**Netherlands****Orofacial Clefts****OFC Epidemiology 3.2: Mortality data: Vital registration data**

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

**Netherlands****Orofacial Clefts****OFC 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                           |                    |               |                  |               |                   |               |



**Netherlands****Orofacial Clefts****OFC Epidemiology 3.4: Summary mortality estimates**

| Indicator  | Your estimates | Range | PHGDB minimum estimates | Chosen estimates | Range | Source |
|--|----------------|-------|-------------------------|------------------|-------|--------|
| Year of data collection  |                |       | 0                       |                  |       |        |
| Number of annual deaths in affected persons                        |                |       | 134                     |                  |       |        |
| Number of annual live births (in 1000s)                            |                |       | 190                     |                  |       |        |
| Number of annual affected neonatal deaths                          |                |       | 8                       |                  |       |        |
| Number of affected neonatal deaths / 1000 LB                       |                |       | 0.04                    |                  |       |        |
| Number of annual affected infant deaths                            |                |       | 9                       |                  |       |        |
| Number of affected infant deaths/ 1000 LB                          |                |       | 0.05                    |                  |       |        |
| Number of annual affected under-5 deaths                           |                |       | 9                       |                  |       |        |
| Number of affected under-5 deaths / 1000 LB                        |                |       | 0.05                    |                  |       |        |
| Mean life expectancy at birth in affected people                   |                |       | 73.0                    |                  |       |        |
| 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.

**Netherlands****Orofacial Clefts****OFC Epidemiology 3.5: Sub-population variation in mortality**

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

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

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

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

**Netherlands****Orofacial Clefts****OFC 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.

**Netherlands****Orofacial Clefts****OFC 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.

**Netherlands****Orofacial Clefts****OFC 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                       |   |       |  |       |
| <b>PHGDB</b>            |   |       |  |       |
| <b>Chosen estimates</b> |   |       |  |       |

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

**Netherlands****Orofacial Clefts****OFC 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)

**Netherlands****Orofacial Clefts****OFC Interventions 1: Effect of folic acid fortification\***

This sheet allows you to estimate the potential reduction in OFC prevalence through fortification of food with folic acid. Please start by entering values reflecting your current situation. If you have no fortification programme, enter 0 for coverage. Below, you may adjust dosage and coverage levels to demonstrate the effects of different intervention scenarios.

| Current situation  |  | Notes           |
|--|--|-----------------|
| Present estimated OFC prevalence per 1000 TB   |  |                 |
| Present dosage (ppm)   |  | Range: 1.5 to 3 |
| Present coverage of fortification  |  | Range: 0 to 1   |
| <sup>1</sup> Baseline OFC prevalence per 1000 TB, with no folic acid fortification** |  |                 |

| Potential scenarios, based on your present situation                                   |       |                           |
|--|-------|---------------------------|
| Vary dosage (ppm)  |       | Range: 1.5 to 3           |
| Vary proportional population coverage  |       | Range: 0 to 1             |
| Estimated reduction in OFCs through folic acid fortification, per 1000 TB <sup>2</sup> | 0.000 | Do not delete this value! |
| Resulting prevalence of OFCs after folic acid fortification, per 1000 TB               | 0.000 | Do not delete this value! |

ppm = parts per million

TB = total births (live births + still births)

\* The effect of folic acid on OFCs is assumed to be 25% of the effect on neural tube defects.

The regression formula underlying the effect on neural tube defects is given in the NTD Calculator in this Toolkit.

\*\* Not considering the effects of other interventions on prevalence.

<sup>1</sup> $(\text{Present estimated prevalence} - (1.07 * \text{coverage} * 0.25) + (0.15 * \text{ppm} * \text{coverage} * 0.25)) / (1 - 0.88 * \text{coverage} * 0.25))$

<sup>2</sup> $((0.25 * (\text{Baseline OFC} - (1.07 * \text{coverage} + 0.12 * \text{baseline OFC} * \text{coverage} - 0.15 * \text{dosage} * \text{coverage} + \text{baseline} - \text{baseline} * \text{coverage}))))$

<sup>3</sup>Baseline OFC prevalence – estimated reduction in OFC after fortification

**Netherlands****Orofacial Clefts****OFC Interventions 2: Effect of folic acid supplementation**

| <b>Effect of supplementation (with no fortification)</b>          |              | Notes   |
|---|--------------|---|
| Baseline prevalence with no folic acid intervention (per 1000 TB) |              | This can be taken from the appropriate cell (baseline OFC prevalence) in sheet OFC-Interv1.                       |
| Maximum proportional reduction (assuming 100% coverage)           | 0.18         | This value is fixed at 0.18   |
| Population supplementation coverage                               |              | Range: 0 to 1   |
| Actual proportional reduction                                     | 0            | Maximum proportional reduction x Coverage   |
| Actual prevalence reduction (per 1000 TB)                         | 0.000        | Baseline incidence x Actual proportional reduction  |
| <b>New prevalence</b>   | <b>0.000</b> | Baseline prevalence with no intervention -((Maximum prop. Reduction x Pop. Supp. Coverage) X Baseline prevalence) |
| % prevalence reduction  | #DIV/0!      | 1-(New prevalence/Baseline prevalence)  |
| Absolute prevalence reduction (per 1000 TB)                       | 0.000        | Baseline prevalence – New prevalence  |

Now you can see below the potential combined effect of folate fortification and supplementation:

|  |                       |  |
|--|-----------------------|--|
| <b>Additional effect of supplementation, given fortification</b> |                       | This value can be changed.   |
|  | <b>New prevalence</b> |  |
| After fortification  |                       | This can be taken from the appropriate cell (resulting OFC prevalence) in sheet OFC-Interv1. |
| After supplementation  | 0.000                 | Requires input in blank cells above  |
| After fortification and supplementation <sup>1</sup>             |                       | Requires input in blank cells above  |

TB = total births (live births + still births)

OFC = orofacial clefts

<sup>1</sup>Prevalence after fortification-(Additional effect of supplementation\*prevalence after supplementation)



**Netherlands****Orofacial Clefts****OFC Interventions 3: Effect of newborn diagnosis and treatment**

|   |  |               |
|---|--|---------------|
| Baseline birth prevalence of orofacial clefts, per 1000 LB                                    |  |               |
| Variables   |  |               |
| Coverage of newborn screening   |  | Range: 0 to 1 |
| Proportion of positive-screened patients receiving treatment                                  |  | Range: 0 to 1 |
| Effectiveness of treatment  |  | Range: 0 to 1 |
| Results   |  |               |
| Proportional reduction of prevalence of untreated OFCs through NBS and treatment <sup>1</sup> |  | 0             |
| Prevalence of untreated OFCs after newborn screening and treatment, per 1000 LB <sup>2</sup>  |  | 0             |

LB = live births

OFCs = orofacial clefts

NBS = newborn screening

<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 untreated cases of OFC X Baseline birth prevalence)

**Netherlands****Orofacial Clefts****OFC Needs assessment 1: Quantitative baseline****Table OFC-NA1a Burden of Orofacial Clefts in pregnancy, at birth and at population level**

| Indicator                                | Chosen estimates |                     |                     | Notes                 |
|--|------------------|---------------------|---------------------|-----------------------|
|  | Number (n)       | n/1000 total births | Range of prevalence |                       |
| 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 OFC-NA1b Orofacial Clefts mortality indicators**

| Indicator  | Chosen estimates |           |                     | Notes                 |
|--|------------------|-----------|---------------------|-----------------------|
|  | Number (n)       | n/1000 LB | Range of prevalence |                       |
| Annual overall mortality                         | 0                |           | 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 affected people | 0                |           | 0                   | Drawn from sheet E3.4 |

**Netherlands****Orofacial Clefts****OFC Needs assessment 3: Quantitative assessment of interventions**

| <b>Table OFC-NA3a</b> | <b>Estimated prevalence in the absence of interventions for Orofacial Clefts</b> |                     |
|-----------------------|--|---------------------|
| Indicator             | Number (n)   | Prevalence (n/1000) |
| Potential live births |  |                     |
| Potential stillbirths |  |                     |

| <b>Table OFC-NA3b</b>                 | <b>Current situation in relation to interventions before birth</b> |                   |                       |
|---------------------------------------|--|-------------------|-----------------------|
| Intervention                          | Coverage (%)   | Cases averted (n) | Cases averted/1000 TB |
| Effect of family planning, education  |  |                   |                       |
| Effect of multivitamin and folic acid |  |                   |                       |
| Effect of prenatal diagnosis          |  |                   |                       |
| Overall effect                        |  |                   |                       |

| <b>Table OFC-NA3c</b>                 | <b>Target situation in relation to interventions before birth</b> |                   |                       |
|---------------------------------------|---|-------------------|-----------------------|
| Intervention                          | Coverage (%)  | Cases averted (n) | Cases averted/1000 TB |
| Effect of family planning, education  |   |                   |                       |
| Effect of multivitamin and folic acid |   |                   |                       |
| Effect of prenatal diagnosis          |   |                   |                       |
| Overall effect                        |   |                   |                       |

| <b>Table OFC-NA3d</b>             | <b>Current situation in relation to interventions after birth</b> |                   |                       |
|-----------------------------------|---|-------------------|-----------------------|
| Intervention                      | Coverage (%)  | Cases managed (n) | Cases managed/1000 TB |
| Effect of newborn diagnosis       |   |                   |                       |
| Effect of feeding advice          |   |                   |                       |
| Effect of surgical treatment      |   |                   |                       |
| Effect of social care and support |   |                   |                       |
| Effect of rehabilitation          |   |                   |                       |
| Overall effect                    |   |                   |                       |
|                                   |   |                   |                       |
|                                   |   |                   |                       |

| Table OFC-NA3e                    | Target situation in relation to interventions after birth |                   |                       |
|-----------------------------------|---|-------------------|-----------------------|
| Intervention                      | Coverage (%)  | Cases managed (n) | Cases managed/1000 TB |
| Effect of newborn diagnosis       |   |                   |                       |
| Effect of feeding advice          |   |                   |                       |
| Effect of surgical treatment      |   |                   |                       |
| Effect of social care and support |   |                   |                       |
| Effect of rehabilitation          |   |                   |                       |
| Overall effect                    |   |                   |                       |

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