# PHG Needs Assessment Calculator Germany Orofacial Clefts

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### Germany Shared Data

Demographic, maternal health and socio-economic indicators

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

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

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

Number of persons by age-group and sex		Estimates		Yo	ur estimat	es		Chosen es	timates
Age group	Male	Female	Total	Male	Female	Total	Male	Female	Total
0-4 years	1749452	1660156	3409608			0			0
5-9 years	1869921	1777806	3647727			0			0
10-14 years	2035044	1930255	3965299			0			0
15-19 years	2214032	2103040	4317072			0			0
20-24 years	2516653	2417804	4934457			0			0
25-29 years	2522868	2455552	4978420			0			0
30-34 years	2394924	2336333	4731257			0			0
35-39 years	2660706	2583366	5244072			0			0
40-44 years	3510685	3353895	6864580			0			0
45-49 years	3575913	3447397	7023310			0			0
50-54 years	3053638	2999569	6053207			0			0
55-59 years	2681496	2742416	5423912			0			0
60-64 years	2118460	2189134	4307594			0			0
65+ years	7199814	9701928	16901742			0			0
Total	0	0	81802257	0	0	0	0	0	0
Female population aged 15-44 years		0			-			-	
Data year		2010 report	ed in 2011						
Source, Year			UN 2011						

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

Ethnic group	Number	% population

- 1		
- 1		

Fertility and mortality	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Crude birth rate: live births (LB) / year / 1000 population	8	Unicef, 2007				
Still birth rate (SB): Still births (SB) / year / 1000 total births	2	WHO, 2009				
Total births in 1000s (LB+SB) per year	678	Unicef, 2007				
Infant mortality rate: infant deaths / 1000 LB / year	3	UNICEF				
Under-5 mortality rate: U5 deaths / 1000 LB / year	4	UNICEF				
Percentage births in women >35 years						
Life expectancy at birth (yrs)	80	WHO, 2009				
% of marriages consanguineous						

Maternal health	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Prenatal visits – at least 1 visit (%)	100	WHO, 2004				
Prenatal visits – at least 4 visits (%)						
Births attended by skilled health personnel (%)	100	WHO, 2006				
Contraception prevalence rate (%)						
Unmet need for family planning (%)						
Total fertility rate	1.3	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						

Coole accuemia indicatore	Estimate	Sauras Vaar	Your	Source,		Source,
Socio-economic indicators	Estimate	Source, Year	estimate	Year	estimate	Year
Gross national income per capita (PPP int. \$)	35950	WHO, 2008				
% population living on < US\$1 per day						
Birth registration coverage (%)	>90	WHO, 2008				
Death registration coverage (%)	90-100	WHO, 2006				

LB = live births

PPP = purchasing power parity

SBA = skilled birth attendant

Germany 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.

Hoolth Expanditure	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Health Expenditure		1 2 2 2 2	estimate	rear	estimate	rear
Per capita total expenditure on health (PPP int. \$)	4129	WHO, 2009				
Total expenditure on health as percentage of GDP	11.3	WHO, 2009				
Per capita government expenditure on health (PPP int. \$)	3124	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	75.7	WHO, 2009				
Out-of-pocket expenditure as percentage of private expenditure on health	53.9	WHO, 2009				
Private expenditure on health as percentage of total expenditure on health	21.2	WHO, 2009				
General government expenditure on health as percentage of total government expenditure	18.0	WHO, 2009				

		Source,	Your	Source,	Chosen	Source,
Health Workforce	Estimate	Year	estimate	Year	estimate	Year
Number of nursing and midwifery personnel	895000	WHO, 2008				
Nursing and midwifery personnel density (per 10,000 population)	108.2	WHO, 2008				
Number of physicians	292129	WHO, 2008				
Physician density (per 10 000 population)	35.31	WHO, 2008				
Number of obstetricians						
Number of paediatricians						
Number of paediatric surgeons						
Number of paediatric cardiac surgeons						

Number of paediatric neurosurgeons			
Number of clinical geneticists			
Number of genetic counsellors			
Number of community health workers			
Number of skilled birth attendants (SBA)			
Density of SBA			
Number of lab staff providing cytogenetic testing			
Number of lab staff providing molecular genetics			
Number of lab staff providing biochemical tests for genetics			
Number of skilled health attendants			

Infrastructure	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Number of maternity units						
Number of services providing specialised care for people with CD						
Number of family planning services						
Number of preconception services						
Number of services providing prenatal care						
Number of services providing newborn care						
Number of facilities providing genetic services						
Number of laboratories providing cytogenetics						
Number of laboratories providing molecular genetics Number of laboratories providing biochemical tests for genetics						
Number of facillities for terminations of pregnancies for fetal defects						

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

CD = congenital disorders

Germany Orofacial Clefts

**OFC Epidemiology 1.1: Country epidemiology** 

Year of estimate	Epidemiological indicator	Your estimates	Range	PHGDB minimum estimates	Chosen estimates	Range	Source
Live birth prevalence (LB)   2.18   5tillbirth prevalence (SB)   0.00   1.00	Year of estimate						
Stillbirth prevalence (SB)   0.00	valence at birth and by age-group(/10	0)					
Total birth prevalence (LB+SB)  All age groups  1.63  1.98  1.4 year olds  1.98  5.14 year olds  1.90  45+ year olds  1.26  Number of cases by age group  Annual live births  All age groups  1.498  All age groups  Annual live births  1,498  All age groups  134,333  41 year olds  1.465  1.4 year olds  5,859  5-14 year olds  15-44 year olds  16,346  15-44 year olds  45+ year olds  46,115  No. of cases by level of impairment  No or minor disability*  Moderate disability**  20,150  Severe disability***  20,150  Mortality and morbidity  Mean life expectancy (yrs)  No. deaths < 1yr  No. deaths < 1yr  No. deaths < 5 yrs  33  No. deaths < 5 yrs	birth prevalence (LB)			2.18			
All age groups  1.63  1.98  1.4 year olds  1.98  1.98  5.14 year olds  1.90  1.90  45+ year olds  1.26  Number of cases by age group  Annual live births  All age groups  1.4,488  All age groups  1.4,485  1.4 year olds  1.4,465  1.4 year olds  5.859  5-14 year olds  15-44 year olds  15-44 year olds  15-49 year olds  15-40 year olds  15-41 year olds  15-41 year olds  15-42 year olds  15-43 year olds  15-44 year olds  15-45 year olds  15-47 year olds  15-48 year olds  15-49 year olds  15-49 year olds  15-40 year olds  15-41 year olds  15-42 year olds  15-43 year olds  15-44 year olds  15-45 year olds  15-46 year olds  15-47 year olds  15-48 year olds  15-49 year olds  15-49 year olds  15-40 year olds  15-41 year olds  15-42 year olds  15-43 year olds  15-44 year olds  15-45 year olds  15-46 year olds  15-47 year olds  15-48 year olds  15-49 year olds  15-40 year olds  15-40 year olds  15-41 year olds  15-41 year olds  15-42 year olds  15-43 year olds  15-44 year olds  15-44 year olds  15-47 year olds  15-48 year olds  15-49 year olds  15-49 year olds  15-40 year olds  15-40 year olds  15-41 year olds  15-42 year olds  15-43 year olds  15-44 year olds  15-45 year olds  15-47 year olds  15-47 year olds  15-48 year olds  15-49 year olds  15-49 year olds  15-40 year olds  16-30 year olds  16-30 year olds  16-30 year olds  16-30 year olds  17-40 year olds  18-40 year olds  18-40 year olds  19-40 year o	birth prevalence (SB)			0.00			
<1 year olds 1.4 year olds 1.98 5.14 year olds 1.95 15-44 year olds 1.90 45+ year olds Number of cases by age group Annual live births All age groups 1,498 All age groups 1,498 1,498 All age groups 1,465 1.4 year olds 1,465 1.4 year olds 5,859 5-14 year olds 16,346 15-44 year olds 46,149 No. of cases by level of impairment No or minor disability* Moderate disability*** 20,150 Severe disability*** Mordality and morbidity Mean life expectancy (yrs) No. deaths < 1yr 33 No. deaths < 5 yrs 33 No. deaths < 5 yrs 33 No. deaths < 5 yrs	al birth prevalence (LB+SB)			2.18			
1-4 year olds       1.98         5-14 year olds       1.95         15-44 year olds       1.90         45+ year olds       1.26         Number of cases by age group         Annual live births       1,498         All age groups       134,333         -1 year olds       1,465         1-4 year olds       5,859         5-14 year olds       64,515         45+ year olds       64,515         45+ year olds       46,149         No. of cases by level of impairment       114,183         No or minor disability*       114,183         Modearde disability***       20,150         Severe disability****       274         Mortality and morbidity       73.0         Mean life expectancy (yrs)       73.0         No. deaths < 1yr	age groups			1.63			
5-14 year olds 1.95 15-44 year olds 1.90 45+ year olds 1.26  Number of cases by age group  Annual live births 1,498 All age groups 3134,333 41 year olds 1.465 1-4 year olds 5,859 5-14 year olds 15-44 year olds 16,346 15-44 year olds 46,115 45+ year olds 46,149 No. of cases by level of impairment No or minor disability* No or minor disability** 20,150 Severe disability*** 274  Mortality and morbidity Mean life expectancy (yrs) No. deaths < 1yr No. deaths < 1yr No. deaths < 5 yrs  No. deaths < 5 yrs	ear olds			1.98			
15-44 year olds	year olds			1.98			
1.26   Number of cases by age group	year olds			1.95			
Number of cases by age group         Annual live births       1,498         All age groups       134,333         <1 year olds	14 year olds			1.90			
Annual live births	year olds			1.26			
Annual live births	nber of cases by age group						
<1 year olds				1,498			
1-4 year olds       5,859         5-14 year olds       16,346         15-44 year olds       64,515         45+ year olds       46,149         No. of cases by level of impairment         No or minor disability*       114,183         Moderate disability**       20,150         Severe disability***       274         Mortality and morbidity         Mean life expectancy (yrs)       73.0         No. deaths < 1yr	age groups			134,333			
5-14 year olds 16,346 15-44 year olds 64,515 45+ year olds 46,149  No. of cases by level of impairment  No or minor disability* 114,183 Moderate disability** 20,150 Severe disability*** 274  Mortality and morbidity  Mean life expectancy (yrs) 73.0 No. deaths < 1yr 33 No. deaths 1-4 yrs 0 No. deaths < 5 yrs 33	ear olds			1,465			
15-44 year olds       64,515         45+ year olds       46,149         No. of cases by level of impairment         No or minor disability*       114,183         Moderate disability**       20,150         Severe disability***       274         Mortality and morbidity         Mean life expectancy (yrs)       73.0         No. deaths < 1yr	year olds			5,859			
45+ year olds       46,149         No. of cases by level of impairment         No or minor disability*       114,183         Moderate disability**       20,150         Severe disability***       274         Mortality and morbidity         Mean life expectancy (yrs)       73.0         No. deaths < 1yr	year olds			16,346			
No. of cases by level of impairment           No or minor disability*         114,183           Moderate disability**         20,150           Severe disability***         274           Mortality and morbidity           Mean life expectancy (yrs)         73.0           No. deaths < 1yr	14 year olds			64,515			
No or minor disability*       114,183         Moderate disability**       20,150         Severe disability***       274         Mortality and morbidity       73.0         Mean life expectancy (yrs)       73.0         No. deaths < 1yr	year olds			46,149			
Moderate disability**       20,150         Severe disability***       274         Mortality and morbidity         Mean life expectancy (yrs)       73.0         No. deaths < 1yr	of cases by level of impairment						
Severe disability***         274           Mortality and morbidity           Mean life expectancy (yrs)         73.0           No. deaths < 1yr	or minor disability*			114,183			
Mortality and morbidity           Mean life expectancy (yrs)         73.0           No. deaths < 1yr	derate disability**			20,150			
Mean life expectancy (yrs)       73.0         No. deaths < 1yr	ere disability***			274			
No. deaths < 1yr	tality and morbidity						
No. deaths 1-4 yrs         0           No. deaths < 5 yrs	an life expectancy (yrs)			73.0			
No. deaths < 5 yrs				33			
, and the same of	deaths 1-4 yrs			0			
	deaths < 5 yrs			33			
Infant mortality / 1000 LB 0.05	nt mortality / 1000 LB			0.05			
Under-5 mortality / 1000 LB 0.05	ler-5 mortality / 1000 LB			0.05			
Years of life lost	rs of life lost						

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

Germany
Orofacial Clefts
OFC Epidemiology 1.2: International comparison

	Your chosen		Comparison	
Epidemiological indicator	estimates	Country	Region	World
Prevalence at birth and by age-group (/1000 people)			(Europe, Western	n)
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		1.63		
<1 year olds		1.98		
1-4 year olds		1.98		
5-14 year olds		1.95		
15-44 year olds		1.90		
45+ year olds		1.26		
Number of cases by age-group				
Annual live births		1,498	6,681	156,935
All age groups		134,333	538,630	3,872,892
<1 year olds		1,465		
1-4 year olds		5,859	34,016	486,788
5-14 year olds		16,346	72,141	937,005
15-44 year olds		64,515	259,807	1,826,259
45+ year olds		46,149	172,666	622,840
No. cases by level of impairment				
No or minimum disability*		114,183	457,835	2,927,757
Moderate disability**		20,150	80,794	631,750
Severe disability***		274	0	313,385
Mortality and morbidity				
Mean life expectancy (yrs)		73.0		
No. deaths < 1yr		33	147	47,843
No. deaths 1-4 yrs		0	0	4,837
No. deaths < 5 yrs		33	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				
B = live hirths *Renaired OFC, effective cure ** Renaired OFC	recidual probleme **	**I Inrenaired OEC (se	e hackground chanter)	

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

# Germany

#### **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).

	Number of affected live births	LB prevalence / 1000 TB	Comments
Best estimate			
Lower estimate			
Higher estimate			
	Number of affected still births	SB prevalence / 1000 TB	Comments
Best estimate			
Lower estimate			
Higher estimate			

TB = total births (live births + stillbirths)

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			

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

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.			
Basic Numbers			
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			]
Live birth prevalence: recorded and estimated			
Recorded live birth prevalence (affected recorded live births / 1000 total births)	#DIV/0!	#DIV/0!	
Estimated completeness of recording: what proportion of true affected live births in your data source were recorded?			Range: 0 to 1
Estimated coverage of recorded live births (number of recorded live births / total live births in country or territory)			Range: 0 to 1
Estimated live birth prevalence (recorded prevalence / completeness)	#DIV/0!	#DIV/0!	
Estimated true number of affected live births in data source (number of recorded affected live births / completeness)	#DIV/0!	! #DIV/0!	
Estimated number of affected live births in total population (number of affected live births from data source / (coverage x completeness))	#DIV/0!	#DIV/0!	
Stillbirth prevalence: recorded and estimated			
Recorded stillbirth prevalence (affected recorded still births / 1000 recorded total births)	#DIV/0!	#DIV/0!	
Estimated completeness of recording: what proportion of true affected stillbirths in your data source were recorded?			Range: 0 to 1
Estimated coverage of recorded stillbirths (number of recorded still births / total still births in country or territory)			Range: 0 to 1
Estimated stillbirth prevalence (recorded prevalence / completeness)	#DIV/0!	#DIV/0!	
Estimated true number of affected stillbirths in data source (number of recorded affected still births / completeness)	#DIV/0!	#DIV/0!	
Estimated number of affected still births in total population (number of affected still births from data source / (coverage x completeness))	#DIV/0!	#DIV/0!	

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

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

Estimates for the whole country/territory	Number of affected live births	LB prevalence / 1000 TB
Best estimate		
Lower estimate		
Higher estimate		
	N	0D 1 1 1000 ED
Estimates for the whole country/territory	Number of affected stillbirths	SB prevalence / 1000 TB
Best estimate  Best estimate	Number of affected stillbirths	SB prevalence / 1000 TB
	Number of affected stillbirths	SB prevalence / 1000 TB

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

OFC Epidemiology 2.4: Summary of affected pregnancies

Indicator	Your estimates	Range	PHGDB minimum estimates	Chosen estimates	Range	Source
Number of annual affected live births			1,498			
Annual birth prevalence / 1000 TB			2.18			
Number of annual affected stillbirths			0			
Stillbirth prevalence / 1000 TB / year			0.00			

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

## 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)

# Germany

#### **Orofacial Clefts**

OFC Epidemiology 3.1: Mortality data: Research studies

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

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

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

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

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	
Registered data	
Total registered live births	
Registered condition-specific neonatal deaths (first 28 days of life)	
Registered condition-specific infant deaths (first year of life)	
Registered condition-specific under-5 deaths (first 5 years of life)	
Registered condition-specific neonatal mortality ratio (condition-specific neonatal deaths / 1000 live births in the same year)	#DIV/0!
Registered condition-specific infant mortality (condition-specific infant deaths / 1000 live births in the same year)	#DIV/0!
Registered condition-specific under-5 mortality (condition-specific under-5 deaths / 1000 live births in the same year)	#DIV/0!

Adjustment for under-ascertainment of cause of death and sub-registration of deaths: Enter estimates in the highlighted cells. It is not always possible to adjust the estimates, in which case you may give the value '1', accepting that the estimates in these cases will usually be biased towards low values. (Or you may move to the next section.)

It is assumed that under-ascertainment is stable across age-groups; if ascertainment varies by age-group, you could use separate estimates

It is assumed that under-ascertainment is stable across age-groups; if ascertainment varies by age-group, you could use separate estimates for each age group.

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

OFC Epidemiology 3.3: Mortality data: Other sources

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

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

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

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

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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			1,502			
Number of annual live births (in 1000s)			687			
Number of annual affected neonatal deaths			30			
Number of affected neonatal deaths / 1000 LB			0.04			
Number of annual affected infant deaths			33			
Number of affected infant deaths/ 1000 LB			0.05			
Number of annual affected under-5 deaths			33			
Number of affected under-5 deaths / 1000 LB			0.05			$\neg$
Mean life expectancy at birth in affected people			73.0			
Other indicators (e.g. survival following surgical procedure, etc)						

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

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

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

OFC Epidemiology 4.1: Population prevalence: Research studies

Study, year, site	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			

OFC Epidemiology 4.2: Population prevalence: Other sources

Source, year, site	Data quality and representativeness	Main findings

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

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

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

**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				
PHGDB				
Chosen estimates				

OFC Epidemiology 4.4: Sub-population prevalence variation

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

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

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

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

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

<sup>\*\*</sup> Not considering the effects of other interventions on prevalence.

<sup>&</sup>lt;sup>1</sup>(Present estimated prevalence-(1.07\*coverage\*0.25)+(0.15\*ppm\*coverage\*0.25))/(1-0.88\*coverage\*0.25)))

<sup>&</sup>lt;sup>2</sup>((0.25\*(Baseline OFC-(1.07\*coverage+0.12\*baseline OFC\*coverage-0.15\*dosage\*coverage+baseline-baseline\*coverage))))

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

**OFC Interventions 2: Effect of folic acid supplementation** 

Effect of supplementation (with no fortification)	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

New prevalence	Baseline prevalence with no intervention -((Maximum prop. Reduction x Pop. Supp. Coverage) X Baseline <b>0.000</b> prevalence)
% prevalence reduction	#DIV/0! 1-(New prevalance/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:

Additional effect of supplementation, given	This value can be changed.	
fortification		

	New prevalence	
		This can be taken from the appropriate cell (resulting
After fortification		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)

# **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>&</sup>lt;sup>1</sup>Coverage of newborn screening X Proportion of screen-positive cases receiving treatment X Effectiveness of treatment

<sup>&</sup>lt;sup>2</sup>Baseline birth prevalence – (Proportional reduction of untreated cases of OFC X Baseline birth prevalence)

**OFC Needs assessment 1: Quantitative baseline** 

Table OFC-NA1a Burden of Orofacial Clefts in pregnancy, at birth and at population level

		Chosen estimates		
Indicator	Number (n)	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	0	0	0	Drawn from sheet E1.1
groups)				

Table OFC-NA1b Orofacial Clefts mortality indicators

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

# **OFC Needs assessment 3: Quantitative assessment of interventions**

I ania ()=(Nia (a	Estimated prevalence in the absence of interventions for Orofacial Clefts		
Indicator	Number (n)	Prevalence (n/1000)	
Potential live births			
Potential stillbirths			

Table OFC-NA3b	Current situation in relation to interventions before birth			
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				

Table OFC-NA3c	Target situation in relation to interventions before birth			
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				

Table OFC-NA3d	Current 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-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 outo	comes			
	Current situation		Target situation		
Indicator	Annual number (n)	Prevalence (n/1000)	Annual number (n)	Prevalence (n/1000)	
Estimated affected pregnancies					
Live births (LB)	0	0			
Stillbirths (SB)	0	0			
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			