

PHG Needs Assessment Calculator
United Kingdom
Orofacial Clefts

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(There is no sheet OFC-NA2.)

Note: The Calculator sheets already contain modelled estimates from the PHGDB; note that these estimates do not include OFCs associated with chromosomal disorders and other structural malformations.

United Kingdom

Shared Data

Demographic, maternal health and socio-economic indicators

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

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

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

Number of persons by age-group and sex Age group	Estimates			Your estimates			Chosen estimates		
	Male	Female	Total	Male	Female	Total	Male	Female	Total
0-4 years	2548402	2422427	4970829			0			0
5-9 years	2166818	2055210	4222028			0			0
10-14 years	1833813	1772143	3605956			0			0
15-19 years	1631272	1575275	3206547			0			0
20-24 years	1394941	1350975	2745916			0			0
25-29 years	1184126	1158525	2342651			0			0
30-34 years	987662	981479	1969141			0			0
35-39 years	806089	817220	1623309			0			0
40-44 years	624348	656620	1280968			0			0
45-49 years	494742	529860	1024602			0			0
50-54 years	378954	411344	790298			0			0
55-59 years	292240	319199	611439			0			0
60-64 years	218171	235596	453767			0			0
65+ years	381938	452692	834630			0			0
Total	14943516	14738565	29682081	0	0	0	0	0	0
Female population aged 15-44 years		6540094			-			-	
Data year	2007 reported in								
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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Fertility and mortality	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Crude birth rate: live births (LB) / year / 1000 population	12.20	Unicef, 2013				
Still birth rate (SB): Still births (SB) / year / 1000 total births	3.50	WHO, 2009				
Total births in 1000s (LB+SB) per year	761	Unicef, 2013				
Infant mortality rate: infant deaths / 1000 LB / year	4.4	Unicef, 2013				
Under-5 mortality rate: U5 deaths / 1000 LB / year	5.1	Unicef, 2013				
Percentage births in women >35 years						
Life expectancy at birth (yrs)	80.17	Unicef, 2013				
% of marriages consanguineous						

Maternal health	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Prenatal visits – at least 1 visit (%)	–	Unicef, 2013				
Prenatal visits – at least 4 visits (%)	–	Unicef, 2013				
Births attended by skilled health personnel (%)	–	Unicef, 2013				
Contraception prevalence rate (%)	84.0	Unicef, 2013				
Unmet need for family planning (%)						
Total fertility rate	1.87	Unicef, 2013				
% home births						
% births at health care services	–	Unicef, 2013				
Newborn health	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Number of neonatal examinations by SBA / trained staff						
% neonatal examinations by SBA/ trained staff						

Socio-economic indicators	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Gross national income per capita (PPP int. \$)	36970	Unicef, 2013				
% population living on < US\$1 per day		Unicef, 2013				
Birth registration coverage (%)	>90	WHO 2010				
Death registration coverage (%)	90-100	WHO, 2009				

LB = live births

PPP = purchasing power parity

SBA = skilled birth attendant

United Kingdom
 Shared Data
 Health Services Data

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

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

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

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

Health Expenditure	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Per capita total expenditure on health (PPP int. \$)	3321.7	WHO 2011				
Total expenditure on health as percentage of GDP	9.3	WHO 2011				
Per capita government expenditure on health (PPP int. \$)	2747	WHO 2011				
External resources for health as percentage of total expenditure on health		WHO 2011				
General government expenditure on health as percentage of total expenditure on health	82.7	WHO 2011				
Out-of-pocket expenditure as percentage of private expenditure on health	53.1	WHO 2011				
Private expenditure on health as percentage of total expenditure on health	17.3	WHO 2011				
General government expenditure on health as percentage of total government expenditure	15.9	WHO 2011				

Health Workforce	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Number of nursing and midwifery personnel	621755	WHO, 2009				
Nursing and midwifery personnel density (per 10,000 population)	103	WHO, 2009				
Number of physicians	165317	WHO, 2009				
Physician density (per 10 000 population)	27.39	WHO, 2009				
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 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

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Orofacial Clefts

OFC Epidemiology 1.1: Country epidemiology

Epidemiological indicator	Your estimates	Range	PHGDB minimum estimates	Chosen estimates	Range	Source
Year of estimate						
Prevalence at birth and by age-group(/1000)						
Live birth prevalence (LB)			0.79			
Stillbirth prevalence (SB)			0.01			
Total birth prevalence (LB+SB)			0.80			
All age groups						
<1 year olds						
1-4 year olds						
5-14 year olds						
15-44 year olds						
45+ year olds						
Number of cases by age group						
Annual live births			585			
All age groups						
<1 year olds						
1-4 year olds						
5-14 year olds						
15-44 year olds						
45+ year olds						
No. of cases by level of impairment						
No or minor disability*						
Moderate disability**						
Severe disability***						
Mortality and morbidity						
Mean life expectancy (yrs)			73.8			
No. deaths < 1yr			4			
No. deaths 1-4 yrs			1			
No. deaths < 5 yrs			5			
Infant mortality / 1000 LB			0.01			
Under-5 mortality / 1000 LB			0.01			
Years of life lost						

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

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OFC Epidemiology 1.2: International comparison

Epidemiological indicator	Your chosen estimates	Comparison		
		Country	Region	World
Prevalence at birth and by age-group (/1000 people)		(Europe, Western)		
Live birth prevalence (LB)		0.79	0.96	0.89
Stillbirth prevalence (SB)		0.01	0.01	0.01
Total birth prevalence (LB+SB)		0.80	0.97	0.90
All age groups				
<1 year olds				
1-4 year olds				
5-14 year olds				
15-44 year olds				
45+ year olds				
Number of cases by age-group				
Annual live births		585	4,300	119,796
All age groups				
<1 year olds				
1-4 year olds				
5-14 year olds				
15-44 year olds				
45+ year olds				
No. cases by level of impairment				
No or minimum disability*				
Moderate disability**				
Severe disability***				
Mortality and morbidity				
Mean life expectancy (yrs)		73.8	74.5	28.60
No. deaths < 1yr		4	30	36,310
No. deaths 1-4 yrs		1	8	8,789
No. deaths < 5 yrs		5	38	45,099
Infant mortality / 1000 LB		0.01	0.01	0.30
Under-5 mortality / 1000 LB		0.01	0.01	0.38
Years of life lost				

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

United Kingdom

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)

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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

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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		
Estimates for the whole country/territory	Number of affected stillbirths	SB prevalence / 1000 TB
Best estimate		
Lower estimate		
Higher estimate		

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

United Kingdom

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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			585			
Annual birth prevalence / 1000 TB			0.79			
Number of annual affected stillbirths			9			
Stillbirth prevalence / 1000 TB / year			0.01			

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

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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.

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)

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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
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			

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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 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!	

United Kingdom

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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).

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

United Kingdom

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						
Number of annual live births (in 1000s)			744			
Number of annual affected neonatal deaths			4			
Number of affected neonatal deaths / 1000 LB			0.01			
Number of annual affected infant deaths			4			
Number of affected infant deaths/ 1000 LB			0.01			
Number of annual affected under-5 deaths			5			
Number of affected under-5 deaths / 1000 LB			0.01			
Mean life expectancy at birth in affected			73.8			
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.

United Kingdom

Orofacial Clefts

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

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

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

United Kingdom

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.

United Kingdom

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.

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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				
PHGDB				
Chosen estimates				

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

United Kingdom

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: $\text{Number of affected people} / (\text{Total number of people in population subgroup} / 1000)$

United Kingdom

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 cover. 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
¹ 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 ²	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.

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

$$^2((0.25 * (\text{Baseline OFC} - (1.07 * \text{coverage} + 0.12 * \text{baseline OFC} * \text{coverage} - 0.15 * \text{dosage} * \text{coverage} + \text{baseline} - \text{baseline} * \text{coverage}))))$$
³Baseline OFC prevalence – estimated reduction in OFC after fortification

United Kingdom

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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	0.000	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:

Additional effect of supplementation, given fortification		This value can be changed.
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	New prevalence	
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 ¹		Requires input in blank cells above

TB = total births (live births + still births)

OFC = orofacial clefts

¹Prevalence after fortification-(Additional effect of supplementation*prevalence after supplementation)

United Kingdom

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 ¹	0	
Prevalence of untreated OFCs after newborn screening and treatment, per 1000 LB ²	0	

LB = live births

OFCs = orofacial clefts

NBS = newborn screening

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

²Baseline birth prevalence – (Proportional reduction of untreated cases of OFC X Baseline birth prevalence)

United Kingdom

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		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

United Kingdom

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Table OFC-NA3a	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 outcomes			
	Current situation		Target situation	
Indicator	Annual number (n)	Prevalence (n/1000)	Annual number (n)	Prevalence (n/1000)
Estimated affected pregnancies				
Live births (LB)	0	0		
Stillbirths (SB)	0	0		
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		