

PHG Needs Assessment Calculator**Sweden****Congenital Heart Disease**

Welcome to the PHG Health Needs Assessment Calculator for Congenital Heart Disease. The contents of this file are listed below.

Full name of the sheet	Short name
Country demographic, maternal health and socioeconomic indicators	Demography
Country health service data	HealthServices
CHD Epidemiology 1.1: Country epidemiology	CHD-E1.1
CHD Epidemiology 1.2: International comparison	CHD-E1.2
CHD Epidemiology 2.1: Data on affected pregnancies: Research studies	CHD-E2.1
CHD Epidemiology 2.2: Data on affected pregnancies: Surveillance	CHD-E2.2
CHD Epidemiology 2.3: Data on affected pregnancies: Other sources	CHD-E2.3
CHD Epidemiology 2.4: Summary of affected pregnancies	CHD-E2.4
CHD Epidemiology 2.5: Sub-population variation in affected pregnancies	CHD-E2.5
CHD Epidemiology 3.1: Mortality data: Research studies	CHD-E3.1
CHD Epidemiology 3.2: Mortality data: Vital registration data	CHD-E3.2
CHD Epidemiology 3.3: Mortality data: Other sources	CHD-E3.3
CHD Epidemiology 3.4: Summary mortality estimates	CHD-E3.4
CHD Epidemiology 3.5: Sub-population variation in mortality	CHD-E3.5
CHD Epidemiology 4.1: Population prevalence: Research studies	CHD-E4.1
CHD Epidemiology 4.2: Population prevalence: Other sources	CHD-E4.2
CHD Epidemiology 4.3: Summary of population prevalence	CHD-E4.3
CHD Epidemiology 4.4: Sub-population prevalence variation	CHD-E4.4
CHD Interventions 1: Effect of folic acid fortification	CHD-Interv1
CHD Interventions 2: Effect of folic acid supplementation	CHD-Interv2
CHD Interventions 3: Effects of prenatal screening and pregnancy management	CHD-Interv3
CHD Needs Assessment Calculator 1: Quantitative baseline	CHD-NA1
CHD Needs Assessment Calculator 3: Quantitative assessment of interventions	CHD-NA3

(There is no sheet CHD-NA2.)

Note: The Calculator sheets already contain modelled estimates from the PHGDB; note that these estimates do not include CHD associated with chromosomal disorders (e.g. Down's syndrome) and other non-cardiac malformations.

Sweden**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	281826	266396	548222			0			0
5-9 years	258574	245360	503934			0			0
10-14 years	255238	242048	497286			0			0
15-19 years	328011	310522	638533			0			0
20-24 years	309505	295948	605453			0			0
25-29 years	293280	278479	571759			0			0
30-34 years	296143	283926	580069			0			0
35-39 years	322241	312257	634498			0			0
40-44 years	337930	325130	663060			0			0
45-49 years	315776	305370	621146			0			0
50-54 years	295746	289390	585136			0			0
55-59 years	288996	286358	575354			0			0
60-64 years	312140	313315	625455			0			0
65+ years	753608	937169	1690777			0			0
Total	0	0	9340682	0	0	0	0	0	0
Female population aged 15-44 years		0			-			-	
Data year	2010 reported in 2011								
Source, Year	UN 2011								

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

Ethnic group	Number	% population

Fertility and mortality	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Crude birth rate: live births (LB) / year / 1000 population	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	102	Unicef, 2007				
Infant mortality rate: infant deaths / 1000 LB / year	2	UNICEF				
Under-5 mortality rate: U5 deaths / 1000 LB / year	3	(2011), 2010				
Percentage births in women >35 years		(2011), 2010				
Life expectancy at birth (yrs)	81	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 (%)						
Contraception prevalence rate (%)						
Unmet need for family planning (%)						
Total fertility rate	1.9	WHO, 2009				
% home births						
% births at health care services						
Newborn health	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Number of neonatal examinations by SBA / trained staff						
% neonatal examinations by SBA/ trained staff						

Socio-economic indicators	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Gross national income per capita (PPP int. \$)	37780	WHO, 2008				
% population living on < US\$1 per day						
Birth registration coverage (%)	>90	WHO, 2008				
Death registration coverage (%)	90-100	WHO, 2008				

LB = live births

PPP = purchasing power parity

SBA = skilled birth attendant

Sweden
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. \$)	3690	WHO, 2009				
Total expenditure on health as percentage of GDP	9.9	WHO, 2009				
Per capita government expenditure on health (PPP int. \$)	2902	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	78.6	WHO, 2009				
Out-of-pocket expenditure as percentage of private expenditure on health	92.8	WHO, 2009				
Private expenditure on health as percentage of total expenditure on health	16.6	WHO, 2009				
General government expenditure on health as percentage of total government expenditure	13.8	WHO, 2009				

Health Workforce	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Number of nursing and midwifery personnel	104958	WHO, 2006				
Nursing and midwifery personnel density (per 10,000 population)	115.7	WHO, 2006				
Number of physicians	32495	WHO, 2006				
Physician density (per 10,000 population)	35.83	WHO, 2006				
Number of obstetricians						
Number of paediatricians						
Number of paediatric surgeons						
Number of paediatric cardiac surgeons						
Number of paediatric neurosurgeons						
Number of clinical geneticists						
Number of genetic counsellors						
Number of community health workers						
Number of skilled birth attendants (SBA)						
Density of SBA						
Number of lab staff providing cytogenetic testing						
Number of lab staff providing molecular genetics						

Number of lab staff providing biochemical tests for genetics						
Number of skilled health attendants						

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

PPP = purchasing power parity

GDP = gross domestic product

SBA = skilled birth attendant

CD = congenital disorders

Sweden

Congenital Heart Disease

CHD 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)			4.59			
Stillbirth prevalence (SB)			0.05			
Total birth prevalence (LB+SB)			4.64			
All age groups			1.98			
<1 year old			4.01			
1-4 year olds			4.01			
5-14 year olds			4.18			
15-44 year olds			2.97			
45+ year olds			0.20			
Number of cases by age group						
Annual live births			436			
All age groups			17,792			
<1 year olds			385			
1-4 year olds			1,528			
5-14 year olds			4,660			
15-44 year olds			10,453			
45+ year olds			766			
No. of cases by level of impairment						
No or minor disability			13,300			
Moderate disability*			4,492			
Severe disability*						
Mortality and morbidity						
Mean life expectancy (yrs)			58.8			
No. deaths < 1yr			51			
No. deaths 1-4 yrs			6			
No. deaths < 5 yrs			58			
Infant mortality / 1000 LB			0.54			
Under-5 mortality / 1000 LB			0.61			
Years of life lost						

LB = live births; SB = stillbirths * Moderate = compensated cardiac problems, premature death preceded by average 1 year, and/or exertional disability. Severe = lifelong exertional disability

Sweden

Congenital Heart Disease

CHD: 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)		4.59	4.80	5.08
Stillbirth prevalence (SB)		0.05	0.05	0.05
Total birth prevalence (LB+SB)		4.64	4.85	5.13
All age groups		1.98		
<1 year olds		4.01		
1-4 year olds		4.01		
5-14 year olds		4.18		
15-44 year olds		2.97		
45+ year olds		0.20		
Number of cases by age-group				
Annual live births		436	20,244	674,738
All age groups		17,792	767,384	7,859,530
<1 year olds		385	18,294	278,694
1-4 year olds		1,528	72,657	1,090,174
5-14 year olds		4,660	182,669	2,543,275
15-44 year olds		10,453	480,643	3,868,752
45+ year olds		766	13,121	78,635
No. cases by level of impairment				
No or minor disability		13,300	548,474	2,153,904
Moderate disability*		4,492	218,910	5,705,201
Severe disability*				
Mortality and morbidity				
Mean life expectancy (yrs)		58.8		
No. deaths < 1yr		51	1,950	396,454
No. deaths 1-4 yrs		6	259	12,002
No. deaths < 5 yrs		58	2,209	408,457
Infant mortality / 1000 LB		0.54	0.46	2.99
Under-5 mortality / 1000 LB		0.61	0.52	3.08
Years of life lost				

LB = live births; SB = stillbirths * Moderate = compensated cardiac problems, premature death preceded by average 1 year, and/or exertional disability. Severe = lifelong exertional disability

Sweden**Congenital Heart Disease****CHD 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 CHD-E2.1 of the Tool), enter the best estimates for the prevalence of affected births, still births and terminations in the country, and a range of values to reflect uncertainty or within-country variation.

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

Estimates for the total country/territory	Number of affected live births	LB prevalence / 1000 TB	Comments
Best estimate			
Lower estimate			
Higher estimate			
Estimates for the total country/territory	Number of affected stillbirths	SB prevalence / 1000 TB	Comments
Best estimate			
Lower estimate			
Higher estimate			
Estimates for the total country/territory	Number of terminations of pregnancy due to condition	ToP / 1000 TB	Comments
Best estimate			
Lower estimate			
Higher estimate			

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

Sweden**Congenital Heart Disease****CHD Epidemiology 2.2: Data on affected pregnancies: Surveillance**

Based on surveillance data, enter the best estimates for the prevalence of the condition in live births, stillbirths and pregnancy terminations in the country. Give a range of values to reflect uncertainty and within-country variation, and use comments for information on data quality, uncertainty and representativeness.

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

Estimates for the total country/territory	Number of affected live births	Birth prevalence / 1000 TB	Comments
Best estimate			
Lower estimate			
Higher estimate			

Estimates for the total country/territory	Number of affected stillbirths	Stillbirth prevalence / 1000 TB	Comments
Best estimate			
Lower estimate			
Higher estimate			

Estimates for the total country/territory	Number of ToP due to condition	ToP / 1000 TB	Comments
Best estimate			
Lower estimate			
Higher estimate			

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

Sweden

Congenital Heart Disease

CHD Epidemiology 2.3: Data on affected pregnancies: Other sources

	Source 1:	Source 2:	Notes
Enter year and source of data – use last year with information available.			
Basic Numbers			
Number of affected live births / year, from data source			
Total number of live births / year, from data source			
Number of affected still births / year, from data source			
Total number of stillbirths / year, from data source			
Number of ToP for affected fetus / year from data source			
Total number of affected births / year (live and still)	0	0	
Total number of births / year, from data source	0	0	
Total number of ToP / year, from data source			
Total number of women aged 15-44			
Live birth prevalence: recorded and estimated			
Recorded live birth prevalence (affected recorded live births / 1000 recorded total births)	#DIV/0!	#DIV/0!	
Estimated completeness of recording: what proportion of true affected live births in your data source were recorded?			Range: 0 to 1
Estimated coverage of recorded live births (number of recorded live births / total live births in country or territory)			Range: 0 to 1
Estimated live birth prevalence (recorded prevalence / completeness)	#DIV/0!	#DIV/0!	
Estimated true number of affected live births in data source (number of recorded affected live births / completeness)	#DIV/0!	#DIV/0!	
Estimated number of affected live births in total population (number of affected live births from data source / (coverage x completeness))	#DIV/0!	#DIV/0!	
Stillbirth prevalence: recorded and estimated			
Recorded stillbirth prevalence (affected recorded still births / 1000 recorded total births)	#DIV/0!	#DIV/0!	
Estimated completeness of recording: what proportion of true affected stillbirths in your data source were recorded?			Range: 0 to 1
Estimated coverage of recorded stillbirths (number of recorded still births / total still births in country or territory)			Range: 0 to 1
Estimated stillbirth prevalence (recorded prevalence / completeness)	#DIV/0!	#DIV/0!	
Estimated true number of affected stillbirths in data source (number of recorded affected still births / completeness)	#DIV/0!	#DIV/0!	
Estimated number of affected stillbirths in total population (number of affected still births from data source / (coverage x completeness))	#DIV/0!	#DIV/0!	

ToP prevalence: recorded and estimated			
Recorded ToP prevalence (ToP in affected fetuses / 1000 women aged 15-44)	#DIV/0!	#DIV/0!	
Estimated completeness of recording: what proportion of true affected pregnancy terminations in your data source were recorded?			Range: 0 to 1
Estimated coverage of recorded ToP (number of recorded ToP / total ToP in country or territory)			Range: 0 to 1
Estimated ToP prevalence (recorded prevalence / estimated completeness)	#DIV/0!	#DIV/0!	
Estimated true number of ToP in data source (number of recorded ToP / completeness)	#DIV/0!	#DIV/0!	
Estimated number of ToP in total population (number of ToP from data source / (coverage x completeness))	#DIV/0!	#DIV/0!	

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

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

Estimates for the whole country/territory	Number of affected live births	LB prevalence / 1000 TB
Best estimate		
Lower estimate		
Higher estimate		
Estimates for the whole country/territory	Number of affected still births	SB prevalence / 1000 TB
Best estimate		
Lower estimate		
Higher estimate		
Estimates for the whole country/territory	Number of ToP due to condition	ToP /1000 TB
Best estimate		
Lower estimate		
Higher estimate		

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

Sweden**Congenital Heart Disease****CHD Epidemiology 2.4: Summary of affected pregnancies**

Indicator	Your estimates	Range	PHGDB minimum estimates	Chosen estimates	Range	Source
Number of annual affected live births			436			
Annual birth prevalence / 1000 TB			4.59			
Number of annual affected still births			4			
Stillbirth prevalence / 1000 TB/year			0.05			
Number of terminations of pregnancy in affected fetuses /year			48			
Affected ToP / 1000 TB			0.51			

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

Sweden**Congenital Heart Disease****CHD Epidemiology 2.5: Sub-population variation in affected pregnancies**

If the birth prevalence rates vary by population sub-group (e.g. geographically or by another factor), indicate any population groups with different prevalence estimates from the whole population and describe reasons for variation. If a group is substantially different from the general population, you may wish to conduct a needs assessment for that group alone.

Population sub-group	Number of affected live births	LB prevalence / 1000 TB	Reason for variation

Population sub-group	Number of affected stillbirths	SB prevalence / 1000 TB	Reason for variation

Population sub-group	Number of ToP in affected pregnancies	ToP prevalence / 1000 TB	Reason for variation

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

Sweden**Congenital Heart Disease****CHD Epidemiology 3.1: Mortality data: Research studies**

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

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

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

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

LB = live births

Sweden**Congenital Heart Disease****CHD 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!	

Sweden**Congenital Heart Disease****CHD 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						

Sweden**Congenital Heart Disease****CHD Epidemiology 3.4: Summary mortality estimates**

Indicator	Your estimates	Range	PHGDB minimum estimates	Chosen estimates	Range	Source
Year of data collection						
Number of annual deaths in affected persons			270			
Number of annual live births (in 1000s)			95			
Number of annual affected neonatal deaths			29			
Number of affected neonatal deaths / 1000 LB			0.30			
Number of annual affected infant deaths			51			
Number of affected infant deaths / 1000 LB			0.54			
Number of annual affected under-5 deaths			58			
Number of affected under-5 deaths / 1000 LB			0.61			
Mean life expectancy at birth in affected people			58.8			
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.

Sweden**Congenital Heart Disease****CHD 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

Sweden**Congenital Heart Disease****CHD 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.

Sweden**Congenital Heart Disease****CHD 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.

Sweden**Congenital Heart Disease****CHD Epidemiology 4.3: Summary of population prevalence**

Source of estimates	Estimated total population number of affected persons	Range	Estimated total population prevalence / 1000 persons	Range
1				
2				
3				
4				
5				
PHGDB				
Chosen estimates				

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

Sweden**Congenital Heart Disease****CHD 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)

Sweden**Congenital Heart Disease****CHD Interventions 1: Effect of folic acid fortification**

This sheet allows you to estimate the potential reduction in CHD 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 CHD prevalence per 1000 TB		
Present dosage (ppm)		Range: 1.5 to 3
Present coverage of fortification		Range: 0 to 1
Baseline CHD prevalence per 1000 TB, with no folic acid fortification* ¹		

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 CHDs through folic acid fortification, per 1000 TB ²	0.000	Do not delete this value!
Resulting prevalence of CHDs after folic acid fortification, per 1000 TB ³	0.000	Do not delete this value!

ppm = parts per million

TB = total births (live births + still births)

* The effect of folic acid on CHD 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(Present estimated prevalence-(1.07*coverage*0.25)+(0.15*ppm*coverage*0.25))/(1-0.88*coverage*0.25))

²((0.25*(Baseline CHD-(1.07*coverage+0.12*baseline CHD*coverage-0.15*dosage*coverage+baseline-baseline*coverage))))

³Baseline CHD prevalence – estimated reduction in CHD after fortification

Sweden**Congenital Heart Disease****CHD Interventions 2: Effect of folic acid supplementation**

This sheet allows you to estimate the potential reduction in CHD incidence through folic acid supplementation for pregnant women.

Please enter a value for population coverage of folic acid supplementation, to determine its potential effect.

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 in the previous sheet.
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 prevalence x Actual proportional reduction

New prevalence	0.000	Baseline prevalence -((Maximum prop. Reduction x Population supplementation 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	0.1	This value can be changed.
--	-----	----------------------------

	New prevalence	
After fortification		This can be taken from the appropriate cell above
After supplementation	0.000	Same as new prevalence
After fortification and supplementation		Prevalence after fortification-(Additional effect of supplementation*prevalence after supplementation)

TB = total births (live births + still births)

CHD = congenital heart disease

¹New Prevalence after fortification-(Additional effect of supplementation x Final prev. following supplemen.)

²If New prevalence after fortification < minimum prevalence then use (Baseline prev – min prev)/baseline prevalence

Otherwise use: (Baseline prevalence – new prevalence after fortification and supplementation)/baseline prevalence

Sweden**Congenital Heart Disease****CHD Interventions 3: Effect of prenatal screening and pregnancy management**

Baseline prevalence: fetuses affected by CHD, per 1000 TB		See previous sheet. Use baseline prevalence either before or after folic acid fortification and supplementation.
Variables		
Coverage of prenatal screening		Range: 0 to 1
Proportion of diagnosed pregnancies receiving treatment*		Range: 0 to 1
Effectiveness of treatment		Range: 0 to 1
Results		
Proportional reduction of uncontrolled cases of CHD through PNS and treatment ¹	0%	
Prevalence of uncontrolled CHD after PNS and treatment, per 1000 total births ²	0.000	
Final prevalence: affected live births after PNS & treatment, per 1000 total births ³	0.000	

PNS = prenatal screening

TB = total births (live births + still births)

CHD = congenital heart disease

*Treatment in this case refers to diagnosis and appropriate management of pregnancy

¹Coverage of screening X Proportion of diagnosed pregnancies receiving treatment X Effectiveness of treatment

²Proportional reduction of uncontrolled cases x Baseline prevalence

³Baseline prevalence – prevalence of uncontrolled CHD

CHD Interventions: Effect of prenatal screening and pregnancy termination

Assumption: prenatal services are equally used for cases which would lead to still births and live births.

This could overestimate the impact of ToP if in fact ToP is more likely for severe cases that would result in stillbirth.

Conversely, the impact of ToP could be underestimated if screening is only available to high-income women at lower risk.

100% specificity of prenatal diagnosis assumed.

Baseline prevalence, per 1000 TB (LB + SB)		See previous two sheets. Use baseline either before or after folic acid interventions.
Variables		
Coverage of prenatal screening		Range: 0 to 1
Proportion of screen-positive cases receiving diagnosis		Range: 0 to 1
Proportion of diagnosed cases ending in pregnancy termination		Range: 0 to 1
Results		
% prevalence reduction due to PND & pregnancy termination ¹		0%
Prevalence reduction due to PND & pregnancy termination, per 1000 TB ²		0.000
Final birth prevalence of CHDs after PND & pregnancy termination, per 1000 TB ³		0.000

PNS = prenatal screening

ToP = termination of pregnancy

TB = total births (live births + still births)

¹Coverage of screening X Proportion of screen-positive cases receiving diagnosis x Proportion of cases ending in pregnancy termination

²% prevalence reduction due to PND and termination x Baseline prevalence

³Baseline prevalence – Prevalence reduction due to PND & termination

Sweden**Congenital Heart Disease****CHD Needs Assessment Calculator 1: Quantitative baseline****Table CHD-NA1a Burden of Neural Tube Defects in pregnancy, at birth and at population level**

Indicator	Chosen estimates			Notes
	Number (n)	n/1000 TB	Range of prevalence (/1000 TB)	
Annual affected live births (LB)	0	0	0	Drawn from sheet E2.4
Annual affected stillbirths (SB)	0	0	0	Drawn from sheet E2.4
Annual affected births (LB+SB)	0	0		Drawn from sheet E2.4
Annual affected persons (all age groups)	0	0	0	Drawn from sheet E1.1

Table CHD-NA1b Neural Tube Defects mortality indicators

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

TB = total births (live births + stillbirths)

Sweden**Congenital Heart Disease****CHD Needs Assessment Calculator 3: Quantitative assessment of interventions**

Table CHD-NA3a	Estimated prevalence in the absence of interventions for Neural Tube Defects	
Indicator	Number (n)	Prevalence (n/1000)
Potential live births		
Potential still births		

Table CHD-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 supplementation			
Control of teratogens			
Management of diseases in pregnancy, e.g diabetes			
Rubella prevention			
Effect of prenatal diagnosis			
Overall effect			

Table CHD-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 supplementation			
Control of teratogens			
Management of diseases in pregnancy, e.g diabetes			
Rubella prevention			
Effect of prenatal diagnosis			
Overall effect			

Table CHD-NA3d	Current situation in relation to interventions after birth		
Intervention	Coverage (%)	Cases managed (n)	Cases managed/1000 TB
Effect of newborn screening			
Effect of newborn diagnosis			
Effect of echocardiography services			
Effect of primary care diagnosis			
Effect of paediatric cardiology			
Effect of paediatric cardiac surgery			
Effect of acute clinical care			
Effect of social care and support			
Effect of rehabilitation			
Overall effect			

Table CHD-NA3e	Target situation in relation to interventions after birth		
Intervention	Coverage (%)	Cases managed (n)	Cases managed/1000 TB
Effect of newborn screening			
Effect of newborn diagnosis			
Effect of echocardiography services			
Effect of primary care diagnosis			
Effect of paediatric cardiology			
Effect of paediatric cardiac surgery			
Effect of acute clinical care			
Effect of social care and support			
Effect of rehabilitation			
Overall effect			

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

TB = total births (live births + stillbirths)