# PHG Needs Assessment Calculator India Down's Syndrome

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

(There is no sheet DOWNS-NA2.)

**Shared Data** 

Demographic, maternal health and socio-economic indicators

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

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

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

Number of persons by age-group and sex		Estimates		Your	estimates			Choser	n estimates
Age group	Male	Female	Total	Male	Female	Total	Male	Female	Total
0-4 years	57119612	53327552	1.1E+008			0			0
5-9 years	66734833	61581957	1.3E+008			0			0
10-14 years	65632877	59213981	1.2E+008			0			0
15-19 years	53939991	46275899	1.0E+008			0			0
20-24 years	46321150	43442982	89764132			0			0
25-29 years	41557546	41864847	83422393			0			0
30-34 years	37361916	36912128	74274044			0			0
35-39 years	36038727	34535358	70574085			0			0
40-44 years	29878715	25859582	55738297			0			0
45-49 years	24867886	22541090	47408976			0			0
50-54 years	19851608	16735951	36587559			0			0
55-59 years	13583022	14070325	27653347			0			0
60-64 years	13586347	13930432	27516779			0			0
65+ years	24181980	24923562	49105542			0			0
Total	0	0	1.0E+009	0	0	0	0	0	0
Female population aged 15-44 years		0			-			-	
Data year		2001 report	ted in 2003						
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	23	Unicef, 2007				
Still birth rate (SB) per year per 1000 total births	22	WHO, 2009				
Total births in 1000s (LB+SB) per year	27119	Unicef, 2007				
Infant mortality rate: infant deaths / 1000 LB / year	48	UNICEF				
Under-5 mortality rate: U5 deaths / 1000 LB / year	63	(2)10位度月2010				
Percentage births in women >35 years		(2011), 2010				
Life expectancy at birth (yrs)	65	WHO, 2009				
% of marriages consanguineous						

Maternal health	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Prenatal visits – at least 1 visit (%)	75	WHO, 2008				
Prenatal visits – at least 4 visits (%)	50	WHO, 2008				
Births attended by skilled health personnel (%)	46.9	WHO, 2008				
Contraception prevalence rate (%)	56.3	WHO, 2006				
Unmet need for family planning (%)	12.8	WHO, 2006				
Total fertility rate	2.7	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		Your estimate	· ·	 Source, Year
Gross national income per capita (PPP int. \$)	2930	WHO, 2008			
% population living on < US\$1 per day	41.6	WHO, 2005			
Birth registration coverage (%)	41	WHO, 2006			
Death registration coverage (%)	<25	WHO, 2001			

LB = live births

PPP = purchasing power parity SBA = skilled birth attendant

India 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. \$)	132	WHO, 2009				
Total expenditure on health as percentage of GDP	4.2	WHO, 2009				
Per capita government expenditure on health (PPP int. \$)	43	WHO, 2009				
External resources for health as percentage of total expenditure on health	1.1	WHO, 2009				
General government expenditure on health as percentage of total expenditure on health	32.8	WHO, 2009				
Out-of-pocket expenditure as percentage of private expenditure on health	74.4	WHO, 2009				
Private expenditure on health as percentage of total expenditure on health	67.2	WHO, 2009				
General government expenditure on health as percentage of total government expenditure	4.1	WHO, 2009				

		Source,	Your	Source,	Chosen	Source,
Health Workforce	Estimate	Year	estimate	Year	estimate	Year
Number of nursing and midwifery personnel	1430555	WHO, 2005				
Nursing and midwifery personnel density (per 10,000 population)	13	WHO, 2005				
Number of physicians	660801	WHO, 2005				
Physician density (per 10 000 population)	5.99	WHO, 2005				
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						

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 safe terminations of pregnancies for fetal defects						

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

CD = congenital disorders

India Down's Syndrome

**DOWNS Epidemiology 1.1: Country epidemiology** 

Prevalence at birth and by age-group (/1000)   Live birth prevalence (LB)	Epidemiological indicator	Your estimates	Range	PHGDB minimum estimates	Chosen estimates	Range	Source
Live birth prevalence (LB)   1.29	Year of estimate						
Live birth prevalence (LB)   1.29	Prevalence at birth and by age-group (/1000	))					
Total birth prevalence (LB+SB)				1.29			
All age groups <1 year olds 1-4 year olds 5-14 year olds 5-14 year olds 15-44 year olds 15-44 year olds 15-49 year olds 16-49 year olds 17-49 year olds 18-49 year olds 19-49	Stillbirth prevalence (SB)			0.07			
<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 41 age groups <1 year olds 1-4 year olds 5-14 year olds 5-14 year olds 5-14 year olds 15-44 year olds 5-19 year olds 15-49 year olds 16-49 year olds 17-49 year olds 18-49 year olds 19-49 year olds <p< td=""><td>Total birth prevalence (LB+SB)</td><td></td><td></td><td>1.36</td><td></td><td></td><td></td></p<>	Total birth prevalence (LB+SB)			1.36			
1-4 year olds 5-14 year olds 15-44 year olds 45+ year olds Number of cases by age group Annual live births All age groups	All age groups						
5-14 year olds	<1 year olds						
15-44 year olds 45+ year olds Number of cases by age group Annual live births All age groups <1 year olds 1-4 year olds 1-4 year olds 5-14 year olds 5-14 year olds 5-19 ye	1-4 year olds						
45+ year olds	5-14 year olds						
Number of cases by age group	15-44 year olds						
Annual live births  All age groups  <1 year olds  1-4 year olds  5-14 year olds  5-14 year olds  5-14 year olds  No. of cases by level of impairment  No or minor disability  Moderate disability*  Severe disability*  Mean life expectancy (yrs)  No. deaths < 1 yr  No. deaths < 5 yrs  Infant mortality / 1000 LB  Under-5 mortality / 1000 LB	45+ year olds						
Annual live births  All age groups  <1 year olds  1-4 year olds  5-14 year olds  5-14 year olds  5-14 year olds  No. of cases by level of impairment  No or minor disability  Moderate disability*  Severe disability*  Mean life expectancy (yrs)  No. deaths < 1 yr  No. deaths < 5 yrs  Infant mortality / 1000 LB  Under-5 mortality / 1000 LB	Number of cases by age group						
<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* Severe disability* Mortality and morbidity Mean life expectancy (yrs) No. deaths < 1yr No. deaths < 1yr No. deaths < 5 yrs Infant mortality / 1000 LB Under-5 mortality / 1000 LB				34666			
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* Severe disability* Mortality and morbidity Mean life expectancy (yrs) No. deaths < 1yr No. deaths < 1yr No. deaths < 5 yrs Infant mortality / 1000 LB Under-5 mortality / 1000 LB Under-5 mortality / 1000 LB	All age groups						
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) Mo. deaths < 1yr No. deaths 1-4 yrs No. deaths < 5 yrs Infant mortality / 1000 LB Under-5 mortality / 1000 LB Under-5 mortality / 1000 LB    Severe olds	<1 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) Mean life expectancy (yrs)  No. deaths < 1yr No. deaths 1-4 yrs No. deaths < 5 yrs Infant mortality / 1000 LB Under-5 mortality / 1000 LB Under-5 mortality / 1000 LB	1-4 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)       6         No. deaths < 1yr	5-14 year olds						
No. of cases by level of impairment           No or minor disability   </td <td>15-44 year olds</td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td>	15-44 year olds						
No or minor disability                 Moderate disability*                 Severe disability*                 Mortality and morbidity         Mean life expectancy (yrs)                 Mo. deaths < 1yr	45+ year olds						
Moderate disability*       Severe disability*         Mortality and morbidity         Mean life expectancy (yrs)       6         No. deaths < 1yr	No. of cases by level of impairment						
Severe disability*         Mortality and morbidity           Mean life expectancy (yrs)         6           No. deaths < 1yr	No or minor disability						
Mortality and morbidity           Mean life expectancy (yrs)         6           No. deaths < 1yr	Moderate disability*						
Mean life expectancy (yrs)       6         No. deaths < 1yr	Severe disability*						
No. deaths < 1yr	Mortality and morbidity						
No. deaths 1-4 yrs       6406         No. deaths < 5 yrs	Mean life expectancy (yrs)			6			
No. deaths < 5 yrs	No. deaths < 1yr			16402			
Infant mortality / 1000 LB Under-5 mortality / 1000 LB	No. deaths 1-4 yrs			6406			
Under-5 mortality / 1000 LB				22807			
Under-5 mortality / 1000 LB	Infant mortality / 1000 LB						
	Under-5 mortality / 1000 LB						
Years of life lost 2464359	Years of life lost			2464359			

LB = live births

<sup>\*</sup> For Down's, Moderate = mild mental retardation and Severe = moderate or worse mental retardation (see Background)

India
Down's Syndrome
DOWNS Epidemiology 1.2: International comparison

Epidemiological indicator	Your chosen estimates	Country	Region	World
Prevalence at birth and by age-grou	p (/1000 people)		(Asia, South)	
Live birth prevalence (LB)		1.29	1.41	1.52
Stillbirth prevalence (SB)		0.07	0.08	0.09
Total birth prevalence (LB+SB)		1.36	1.49	1.61
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		34666	51739	202668
All age groups			321650	2703100
<1 year olds				
1-4 year olds			102061	480210
5-14 year olds			137963	734321
15-44 year olds			70175	1149318
45+ year olds			11451	339252
No. cases by level of impairment				
No or minor disability				
Moderate disability*				
Severe disability*				
Mortality and morbidity				
Mean life expectancy (yrs)		6	6	14
No. deaths < 1yr		16402	25,448	84,981
No. deaths 1-4 yrs		6406	9,995	32,644
No. deaths < 5 yrs		22807	35,443	117,624
nfant mortality / 1000 LB				
Under-5 mortality / 1000 LB				
Years of life lost		2464359	3,824,492	13,333,159
LB = live births				

<sup>\*</sup> For Down's, Moderate = mild mental retardation and Severe = moderate or worse mental retardation (see Background)

**Down's Syndrome** 

DOWNS 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 DOWNS-E2.1 of the Tool), enter the best estimates for the prevalence of affected births and terminations in the country, and a range of values to reflect uncertainty or within-country variation.

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

Estimates for the total country/territory	Number of affected live births	LB prevalence / 1000 TB	Comments
Best estimate			
Lower estimate			
Higher estimate			
Estimates for the total country/territory	Number of affected still births	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 women aged 15-44	Comments
Best estimate			
Lower estimate			
Higher estimate			

### **Down's Syndrome**

DOWNS 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, still births 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 still births	Stillbirth prevalence / 1000 TB	Comments
Best estimate			
Lower estimate			
Higher estimate			

	Number of ToP due to condition	ToP / 1000 women aged 15-44	Comments
Best estimate			
Lower estimate			
Higher estimate			

India
Down's Syndrome
DOWNS 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 still births / 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	Number of affected live births + Number of affected still births
Total number of births / year, from data source	0	0	Total number of live births + Total number of still births
Total number of ToP / year, from data source			
Total number of women aged 15-44			
Live birth prevalence: recorded and estimated			
Recorded live birth prevalence (affected recorded live births / 1000 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	#DIV/0!	#DIV/0!	
stillbirths from data source / (coverage x completeness))			

ToP prevalence: recorded and estimated			
Recorded ToP prevalence	#DIV/0!	#DIV/0!	
(ToP in affected fetuses / 1000 women aged 15-44)	1101010	//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			D 01 1
(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 pouncertainty of estimates and within country variation.  If studies are not representative of the national population you may need to we explanation on weighting and help with the calculations).			
Estimates for the whole country/territory	Number of affected live births	LB prevalence /	
Best estimate			
Door Commune			
Lower estimate			
Lower estimate Higher estimate	Number of affected stillbirths	SB prevalence /	
Lower estimate Higher estimate			
Lower estimate Higher estimate Estimates for the whole country/territory			
Lower estimate Higher estimate  Estimates for the whole country/territory  Best estimate			
Lower estimate Higher estimate Estimates for the whole country/territory  Best estimate Lower estimate	affected stillbirths  Number of ToP		
Lower estimate Higher estimate  Estimates for the whole country/territory  Best estimate Lower estimate Higher estimate	affected stillbirths  Number of ToP	1000 TB  ToP /1000 women	
Lower estimate Higher estimate Estimates for the whole country/territory  Best estimate Lower estimate Higher estimate Estimates for the whole country/territory	affected stillbirths  Number of ToP	1000 TB  ToP /1000 women	
Lower estimate Higher estimate  Estimates for the whole country/territory  Best estimate Lower estimate Higher estimate Estimates for the whole country/territory  Best estimate	affected stillbirths  Number of ToP	1000 TB  ToP /1000 women	

India
Down's Syndrome
DOWNS Epidemiology 2.4: Summary of affected pregnancies

Indicator	Your estimates	Range	PHGDB minimum estimates	Chosen estimates	Range	Source
Number of annual affected live births			34666			
Annual birth prevalence / 1000 TB			1.29			
Number of annual affected stillbirths			1941			
Annual still birth prevalence / 1000 TB			0.07			
Number of <b>terminations of pregnancy</b> in affected fetuses/ year						
Affected ToP / 1000 women 15-44/ year	r					

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.

### **Down's Syndrome**

### DOWNS 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

	ToP prevalence / 1000 women aged 15-44	Reason for variation

**Down's Syndrome** 

DOWNS 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			

LB = live births

### **Down's Syndrome**

DOWNS Epidemiology 3.2: Mortality data: Vital registration data

Fill in the blank cells based on your vital registration data.	
Enter year and source of data	
Registered data	
Total registered live births	
Registered condition-specific neonatal deaths (first 28 days of life)	
Registered condition-specific infant deaths (first year of life)	
Registered condition-specific under-5 deaths (first 5 years of life)	
Registered condition-specific neonatal mortality ratio (condition-specific neonatal deaths /(Total registered live births/ 1000))	#DIV/0!
Registered condition-specific infant mortality ((condition-specific infant deaths /(Total registered live births/ 1000))	#DIV/0!
Registered condition-specific under-5 mortality (condition-specific under-5 deaths / (Total registered live births/ 1000))	#DIV/0!

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

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

Estimated completeness of recording: what proportion of deaths in affected persons were registered as such?		Range: 0 to 1
Population coverage: what proportion of the total country/territory population is covered by the vital registration?		Range: 0 to 1
Death ascertainment (population coverage x completeness)	0	
Estimated values for the total country/ territory population		
Estimated number of live births in total population (Total registered live births/population coverage)	#DIV/0!	
Estimated number of neonatal deaths in total population	#DIV/0!	
(number of deaths registered in neonatal period / ascertainment)		
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!	

**Down's Syndrome** 

**DOWNS 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						

India
Down's Syndrome
DOWNS Epidemiology 3.4: Summary mortality estimates

Indicator	Your estimates	Range	PHGDB minimum estimates	Chosen estimates	Range	Source
Year of data collection						
Number of annual deaths in affected persons						
Number of annual live births (in 1000s)			26,000			
Number of annual affected neonatal deaths						
Number of affected neonatal deaths / 1000 LB						
Number of annual affected infant deaths			16402			
Number of affected infant deaths/ 1000 LB						
Number of annual affected under-5 deaths			22807			
Number of affected under-5 deaths / 1000 LB						
Mean life expectancy at birth in affected people			6			
Other indicators (e.g. survival following surgical procedure, etc)						

India
Down's Syndrome

DOWNS Epidemiology 3.5: Sub-population variation in mortality

Age group: neonatal Population sub-group	Cause-specific, group-specific neonatal mortality ratio / 1000 LB	Reason for variation

Age group: infant	Number of deaths in	Cause-specific, group-specific infant Reason for varia		
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		

**Down's Syndrome** 

DOWNS 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			

**Down's Syndrome** 

**DOWNS 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			

**Down's Syndrome** 

**DOWNS 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				

**Down's Syndrome** 

DOWNS 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!	

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)

## India Down's Syndrome

**DOWNS Intervention 1: Effects of maternal age** 

If you have an estimate for the birth prevalence of chromosomal disorders, you can use the Calculator on the left.

If you have an estimate of the proportion of births that are to mothers aged over 35, you can use the Calculator on the right.

Birth prevalence per 1000 TB		
Proportional birth prevalence due to high maternal age <sup>1</sup>		Requires a birth prevalence above
Birth prevalence attributable to high maternal age, per 1000 TB <sup>2</sup>	-0.86	
Baseline prevalence without maternal age effect	0.86	This figure is set at 0.86

Proportion of mothers aged >35		Range: 0 to 1
Estimated birth prevalence per 1000 TB <sup>3</sup>	0.86	
Proportional birth prevalence due to high maternal age <sup>4</sup>	0.00	
Birth prevalence attributable to high maternal age, per 1000 TB <sup>5</sup>	0	
Baseline prevalence without maternal age effect		This figure is set at 0.86

TB = total births (live births + stillbirths)

<sup>1</sup>(Birth prevalence – 0.86)/Birth prevalence

<sup>2</sup>Birth prevalence – Baseline prevalence

<sup>3</sup>0.86+(7\*Proportion of mothers aged >35)

<sup>4</sup>(Estimated birth prevalence- Baseline prevalence)/Estimated birth prevalence

<sup>5</sup>Estimated birth prevalence\*Proportional birth prevalence

### **Down's Syndrome**

### DOWNS Intervention 2: Effect of prenatal screening and diagnosis and pregnancy termination

Note: this makes the simplifying assumption that stillbirth is equally likely in cases that are diagnosed as in cases that are not diagnosed.

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

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

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

100% specificity of prenatal diagnosis assumed.

Birth prevalence (allowing for maternal age effect), per 1000 TB		Can be found i	n sheet DOWNS-Interv1
Variables		_	
Coverage of prenatal screening and diagnosis		Range: 0 to 1	
Proportion of cases diagnosed		Range: 0 to 1	
Proportion of diagnosed cases ending in ToP		Range: 0 to 1	
Results			-
% prevalence reduction due to PNS & ToP¹	0%		
Prevalence reduction due to PNS & ToP, per 1000 TB <sup>2</sup>	0.000		
Final prevalence: affected live births after PNS & ToP, per 1000 TB <sup>3</sup>	0.000		

PNS = prenatal screening
TB = total births (live births + still births)

ToP = termination of pregnancy

 $^{1}\text{Coverage}$  of PNS and diagnosis X Proportion of cases diagnosed x Proportion of cases ending in ToP

<sup>2</sup>% prevalence reduction due to PNS and ToP x Birth prevalence

<sup>3</sup>Birth prevalence – Prevalence reduction due to PNS & ToP

**Down's Syndrome** 

**DOWNS Needs assessment 1: Quantitative baseline** 

Table DOWNS-NA1a Burden of Down's Syndrome in pregnancy, at birth and at population level

		Chosen estima	Notes	
Indicator	` '		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	0 0 0		Drawn from sheet E1.1	
groups)				

Table DOWNS-NA1b Down's Syndrome mortality indicators

	Chosen estimates			Notes
Indicator	Number (n)		Range of prevalence (/1000 LB)	
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 in affected people	0		0	Drawn from sheet E3.4

TB = total births (live births + stillbirths)

LB = live births

### **Down's Syndrome**

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

	Estimated prevalence in the absence of interventions for Down's Syndrome		
Indicator	Number (n)	Prevalence (n/1000)	
Potential live births			
Potential stillbirths			

Table DOWNS-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 prenatal screening					
Effect of prenatal diagnosis					
Effect of ToP					
Overall effect					

Table DOWNS-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 prenatal screening				
Effect of prenatal diagnosis				
Effect of ToP				
Overall effect				

Table DOWNS-NA3d	Current situation in relation to interventions after birth			
Intervention	Coverage (%)	Cases managed (n)	Cases managed/1000 TB	
Effect of newborn diagnosis				
Effect of management and treatment				
Effect of social care and support				
Overall effect				

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

Table DOWNS-NA3f	Current and desired out	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				
Total births (LB+SB)	0	0				
Estimated population prevalence						
All age groups						
Estimated mortality / 1000 live births						
Neonatal deaths	0	0				
nfant deaths	0	0				
Under-5 deaths	0	0				