## PHG Needs Assessment Calculator India Newborn screening

Welcome to the PHG Health Needs Assessment Calculator for Newborn Screening. The contents of this file are listed below.

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India

**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 |       | Cho  | sen estim | ates  |
|--|------|-------------|------------|------|-----------|-------|------|-----------|-------|
| Age group                              | Male | Female      | Total      | Male | Female    | Total | Male | Female    | Total |
| 0-4 years                              | 7808 | 7536        | 15344      |      |           | 0     |      |           | 0     |
| 5-9 years                              | 6514 | 6674        | 13188      |      |           | 0     |      |           | 0     |
| 10-14 years                            | 8047 | 8058        | 16105      |      |           | 0     |      |           | 0     |
| 15-19 years                            | 8735 | 8651        | 17386      |      |           | 0     |      |           | 0     |
| 20-24 years                            | 8553 | 8877        | 17430      |      |           | 0     |      |           | 0     |
| 25-29 years                            | 7422 | 7692        | 15114      |      |           | 0     |      |           | 0     |
| 30-34 years                            | 6469 | 6848        | 13317      |      |           | 0     |      |           | 0     |
| 35-39 years                            | 5895 | 6345        | 12240      |      |           | 0     |      |           | 0     |
| 40-44 years                            | 5644 | 6065        | 11709      |      |           | 0     |      |           | 0     |
| 45-49 years                            | 5107 | 5434        | 10541      |      |           | 0     |      |           | 0     |
| 50-54 years                            | 3988 | 3990        | 7978       |      |           | 0     |      |           | 0     |
| 55-59 years                            | 2977 | 2980        | 5957       |      |           | 0     |      |           | 0     |
| 60-64 years                            | 2142 | 2417        | 4559       |      |           | 0     |      |           | 0     |
| 65+ years                              | 5164 | 6338        | 11502      |      |           | 0     |      |           | 0     |
| Total                                  | 0    | 0           | 172370     | 0    | 0         | 0     | 0    | 0         | 0     |
| Female population aged 15-44 years     |      | 0           |            |      | 0         |       |      | 0         |       |
| Data year                              |      | 2009 report | ed in 2011 |      |           |       |      |           |       |
| Source, Year                           |      |             | UN 2011    |      |           |       |      |           |       |

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

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

| Fertility and mortality  | Estimate | Source, Year | Your estimate | Source, Year | Chosen estimate | Source,<br>Year |
|--|----------|--------------|---------------|--------------|-----------------|-----------------|
| Still der thirt attention in the first hard and a first state of the f | 21.82    | Unicef, 2013 |               |              |                 |                 |
| births   | 22.09    | WHO, 2009    |               |              |                 |                 |
| Total births in 1000s (LB+SB) per year   | 27098    | Unicef, 2013 |               |              |                 |                 |
| Infant mortality rate: infant deaths / 1000 LB / year  | 47.20    | Unicef, 2013 |               |              |                 |                 |
| Under-5 mortality rate: U5 deaths / 1000 LB / year   | 61.30    | Unicef, 2013 |               |              |                 |                 |
| Percentage births in women >35 years   |          |              |               |              |                 |                 |
| Life expectancy at birth (yrs)   | 65.44    | Unicef, 2013 |               |              |                 |                 |
| % of marriages consanguineous  |          |              |               |              |                 |                 |

| Maternal health  | Estimate | Source, Year | Your estimate | Source, Year | Chosen estimate | Source,<br>Year |
|--|----------|--------------|---------------|--------------|-----------------|-----------------|
| Prenatal visits – at least 1 visit (%)                 | 74.2     | Unicef, 2013 |               |              |                 |                 |
| Prenatal visits – at least 4 visits (%)                | 37.0     | Unicef, 2013 |               |              |                 |                 |
| Births attended by skilled health personnel (%)        | 52.3     | Unicef, 2013 |               |              |                 |                 |
| Contraception prevalence rate (%)                      | 54.8     | Unicef, 2013 |               |              |                 |                 |
| Unmet need for family planning (%)                     | 12.8     | WHO, 2006    |               |              |                 |                 |
| Total fertility rate                                   | 2.59     | Unicef, 2013 |               |              |                 |                 |
| % home births  |          |              |               |              |                 |                 |
| % births at health care services                       | 46.90    | Unicef, 2013 |               |              |                 |                 |
| Newborn health   | Estimate | Source, Year | Your estimate | Source, Year | Chosen estimate | Source,<br>Year |
| Number of neonatal examinations by SBA / trained staff |          |              |               |              |                 |                 |
| % neonatal examinations by SBA/ trained staff          |          |              |               |              |                 |                 |

|  |          |              | Your     | Source, Year | Chosen   | Source, |
|--|----------|--------------|----------|--------------|----------|---------|
| Socio-economic indicators                      | Estimate | Source, Year | estimate |              | estimate | Year    |
| Gross national income per capita (PPP int. \$) | 3620     | Unicef, 2013 |          |              |          |         |
| % population living on < US\$1 per day         | 41.6     | Unicef, 2013 |          |              |          |         |
| Birth registration coverage (%)                |          | WHO 2005-    |          |              |          |         |
| Death registration coverage (%)                | <25      | WH9,2009     |          |              |          |         |

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,<br>Year | Your estimate | Source,<br>Year | Chosen estimate | Source,<br>Year |
|--|----------|-----------------|---------------|-----------------|-----------------|-----------------|
| Per capita total expenditure on health (PPP int. \$)                                   | 141.1    | WHO 2011        |               |                 |                 |                 |
| Total expenditure on health as percentage of GDP                                       | 3.9      | WHO 2011        |               |                 |                 |                 |
| Per capita government expenditure on health (PPP int. \$)                              | 43.8     | 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  | 31       | WHO 2011        |               |                 |                 |                 |
| Out-of-pocket expenditure as percentage of private expenditure on health               | 86       | WHO 2011        |               |                 |                 |                 |
| Private expenditure on health as percentage of total expenditure on health             | 69       | WHO 2011        |               |                 |                 |                 |
| General government expenditure on health as percentage of total government expenditure | 8.1      | WHO 2011        |               |                 |                 |                 |

|   |          | 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 |  |  |  |
| Number of skilled health attendants                          |  |  |  |

| Infrastructure   | Estimate | Source,<br>Year | Your estimate | Source,<br>Year | Chosen estimate | Source,<br>Year |
|--|----------|-----------------|---------------|-----------------|-----------------|-----------------|
| Number of maternity units  | Louinato | Tour            | Commuto       | loui            | Commuto         | I Gui           |
| 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 Newborn screening Existing screening programmes for congenital disorders

| Condition                                      | Tick if NBS programme exists | Tick if included in physical examination | Indicate whether NBS is provided at national or subnational level | Condition<br>prevalence<br>per 1000<br>newborns | Prevalence variation and high-risk populations |
|--|------------------------------|--|---|---|--|
| Eye problems                                   |                              |  |   |   |  |
| Signs of heart disease                         |                              |  |   |   |  |
| Developmental dysplasia of hips                |                              |  |   |   |  |
| Genital anomalies (e.g. undescended testicles) |                              |  |   |   |  |
| Orofacial clefts                               |                              |  |   |   |  |
| Dysmorphologies                                |                              |  |   |   |  |
| Hearing loss                                   |                              |  |   |   |  |
| Congenital hypothyroidism                      |                              |  |   |   |  |
| G6PD deficiency                                |                              |  |   |   |  |
| PKU  |                              |  |   |   |  |
| Cystic fibrosis                                |                              |  |   |   |  |
| Thalassaemias                                  |                              |  |   |   |  |
| Sickle cell disease                            |                              |  |   |   |  |
| MCADD  |                              |  |   |   |  |
| CAH  |                              |  |   |   |  |
| Other  |                              |  |   |   |  |

NBS = newborn screening
G6PD = glucose-6-phosphate dehydrogenase
PKU = phenylketonuria
CAH= congenital adrenal hyperplasia
MCADD = medium-chain acyl-CoA dehydrogenase deficiency

#### India Newborn screening Details of newborn screening programmes

| Condition                            | Age at screen | Coverage (%) | Coverage variation and high-risk populations | Estimated proportion of affected newborns detected | Target<br>coverage<br>(%) |
|--------------------------------------|---------------|--------------|--|--|---------------------------|
| Newborn physical ex                  | aminatior     | า            |  |  |                           |
| Basic examination*                   |               |              |  |  |                           |
| Examination for gross abnormalities* |               |              |  |  |                           |
| Detailed physical examination        |               |              |  |  |                           |
| Newborn hearing scr                  | eening        |              |  |  | •                         |
| Crude screening                      |               |              |  |  |                           |
| Equipment based screening            |               |              |  |  |                           |
| Newborn bloodspot s                  | screening     |              |  |  |                           |
| Congenital hypothyroidism            |               |              |  |  |                           |
| PKU                                  |               |              |  |  |                           |
| Cystic fibrosis                      |               |              |  |  |                           |
| Sickle cell disease                  |               |              |  |  |                           |
| G6PD deficiency                      |               |              |  |  |                           |
| MCADD                                |               |              |  |  |                           |
| CAH                                  |               |              |  |  |                           |
| Other                                |               |              |  |  |                           |

PKU = phenylketonuria

G6PD = glucose-6-phosphate dehydrogenase

MCADD = medium-chain acyl-CoA dehydrogenase deficiency

CAH= congenital adreanal hyperplasia

<sup>\*</sup> As defined in the Background document section titled Newborn Screening Tests

## India Newborn screening Effects of NBS and treatment on congenital hypothyroidism

| Baseline birth prevalence of CHT, per 1000 total births*   |   |               |
|--|---|---------------|
| Variables  |   |               |
| Coverage of newborn screening  |   | Range: 0 to 1 |
| Proportion of positive-screened patients receiving diagnosis treatment                                   |   | Range: 0 to 1 |
| Effectiveness of treatment   |   | Range: 0 to 1 |
| Results  |   |               |
| Proportional reduction of uncontrolled cases of CHT through NBS and treatment <sup>1</sup>               | 0 |               |
| Prevalence of uncontrolled CHT after newborn screening and treatment, per 1000 total births <sup>2</sup> | 0 |               |

LB = live births

CHT = congenital hypothyroidism

NBS = newborn screening

<sup>\*</sup> If you don't have data on birth prevalence but do have data on screening, you can estimate birth prevalence by combining the proportion screened positive with the number of total births. (This assumes that screening is randomly distributed in the population).

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

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

#### India Newborn screening Effects of NBS and treatment on G6PD deficiency

| Baseline birth prevalence of G6PD deficiency, 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 uncontrolled cases through NBS and treatment <sup>1</sup>                        | 0 |               |
| Prevalence of uncontrolled G6PD deficiency after newborn screening and treatment, per 1000 LB <sup>2</sup> | 0 |               |

LB = live births

NBS = newborn screening

G6PD = glucose-6-phosphate dehydrogenase

<sup>\*</sup> If you don't have data on birth prevalence but do have data on screening, you can estimate birth prevalence by combining the proportion screened positive with the number of total births. (This assumes that screening is randomly distributed in the population).

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

<sup>&</sup>lt;sup>2</sup>Baseline birth prevalence – (Proportional reduction of uncontrolled cases of G6PD X Baseline birth prevalence)

#### India Newborn screening Effects of NBS and treatment on RHD

| Baseline birth prevalence of RHD, 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 uncontrolled cases through NBS and treatment <sup>1</sup>                       | 0 |               |
| Prevalence of uncontrolled RHD deficiency after newborn screening and treatment, per 1000 LB <sup>2</sup> | 0 |               |

LB = live births

NBS = newborn screening

RHD = Rhesus Haemolytic Disease of Newborn

<sup>1</sup>Coverage of newborn screening X Proportion of screen-positive cases receiving treatment X Effectiveness of treatment

<sup>2</sup>Baseline birth prevalence – (Proportional reduction of uncontrolled cases of RHD X Baseline birth prevalence)

<sup>\*</sup> If you don't have data on birth prevalence but do have data on screening, you can estimate birth prevalence by combining the proportion screened positive with the number of total births. (This assumes that screening is randomly distributed in the population).

## India Newborn screening Effects of NBS and management on sickle cell disease

| Baseline birth prevalence of sickle cell disease, per 1000 LB   |   |               |
|---|---|---------------|
| Variables   |   |               |
| Province screening patients referred for  |   | Range: 0 to 1 |
| management  |   | Range: 0 to 1 |
| Effectiveness of management   |   | Range: 0 to 1 |
| Results   |   |               |
| Proportional reduction in unmanaged cases of SCD through NBS and treatment <sup>1</sup>                     | 0 |               |
| Prevalence of unmanaged sickle cell disease after newborn screening and treatment, per 1000 LB <sup>2</sup> | 0 |               |

LB = live births

SCD = sickle cell disease

NBS = newborn screening

<sup>\*</sup> If you don't have data on birth prevalence but do have data on screening, you can estimate birth prevalence by combining the proportion screened positive with the number of total births. (This assumes that screening is randomly distributed in the population).

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

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

## India Newborn screening Effects of NBS and management on thalassaemias

| Baseline birth prevalence of thalassaemias, per 1000 LB  |   |               |
|--|---|---------------|
| Variables  |   |               |
| Coverage of newborn screening  |   | Range: 0 to 1 |
| Proportion of screen-positive patients referred for treatment  |   | Range: 0 to 1 |
| Effectiveness of management  |   | Range: 0 to 1 |
| Results  |   |               |
| Proportional reduction of prevalence of unmanaged thalassaemias through NBS and treatment <sup>1</sup> | 0 |               |
| Prevalence of unmanaged thalassaemias after newborn screening and treatment, per 1000 LB <sup>2</sup>  | 0 |               |

LB = live births

NBS = newborn screening

\* If you don't have data on birth prevalence but do have data on screening, you can estimate birth prevalence by combining the proportion screened positive with the number of total births. (This assumes that screening is randomly distributed in the population).

<sup>1</sup>Coverage of newborn screening X Proportion of screen-positive cases receiving treatment X Effectiveness of treatment

<sup>2</sup>Baseline birth prevalence – (Proportional reduction of unmanaged cases of thalassaemia X Baseline birth prevalence)

#### India Newborn screening Effects of NBS and treatment on orofacial clefts

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

LB = live births

OFCs = orofacial clefts

NBS = newborn screening

<sup>\*</sup> If you don't have data on birth prevalence but do have data on screening, you can estimate birth prevalence by combining the proportion screened positive with the number of total births. (This assumes that screening is randomly distributed in the population).

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

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

## India Newborn screening Effects of NBS and treatment on phenylketonuria

| Baseline birth prevalence of PKU, 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 clinical cases of PKU through NBS and treatment <sup>1</sup> | 0 |               |
| Prevalence of symptomatic PKU after newborn screening and treatment, per 1000 LB <sup>2</sup>        | 0 |               |

LB = live births

PKU = phenylketonuria

NBS = newborn screening

<sup>1</sup>Coverage of newborn screening X Proportion of screen-positive cases receiving treatment X Effectiveness of treatment

<sup>2</sup>Baseline birth prevalence – (Proportional reduction of prevalence of clinical cases of PKU X Baseline birth prevalence)

<sup>\*</sup> If you don't have data on birth prevalence but do have data on screening, you can estimate birth prevalence by combining the proportion screened positive with the number of total births. (This assumes that screening is randomly distributed in the population).

# India Newborn screening Effects of NBS and management on cystic fibrosis

| Baseline birth prevalence of cycstic fibrosis, per 1000 LB   |   |               |
|--|---|---------------|
| Variables  |   |               |
| คิกษาสมาคา of เกืองเมื่อเกี่ยว sereened patients referred for  |   | Range: 0 to 1 |
| management   |   | Range: 0 to 1 |
| Effectiveness of management  |   | Range: 0 to 1 |
| Results  |   |               |
| Proportional reduction of prevalence of unmanaged cystic fibrosis through NBS and treatment <sup>1</sup> | 0 |               |
| Prevalence of unmanaged cystic fibrosis after newborn screening and treatment, per 1000 LB <sup>2</sup>  | 0 |               |

LB = live births

NBS = newborn screening

\* If you don't have data on birth prevalence but do have data on screening, you can estimate birth prevalence by combining the proportion screened positive with the number of total births. (This assumes that screening is randomly distributed in the population).

<sup>1</sup>Coverage of newborn screening X Proportion of positive-screened patients referred for management X Effectiveness of management

<sup>2</sup>Baseline birth prevalence – (Proportional reduction of prevalence of unmanaged cases X Baseline birth prevalence)