PHG FOUNDATION

# PHG Needs Assessment Calculator United Kingdom Newborn screening

Welcome to the PHG Health Needs Assessment Calculator for Newborn Screening. 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 indicators	HealthServices
Existing screening programmes for congenital disorders	NBS-NA1.1
Details of newborn screening programmes	NBS-NA1.2
Effect of newborn screening and treatment on congenital hypothyroidism	NBS-CHT
Effect of newborn screening and treatment on G6PD deficiency	NBS-G6PD
Effect of newborn screening and treatment on Rhesus haemolytic disease of newborn	NBS-RHD
Effect of newborn screening and management on sickle cell disease	NBS-SCD
Effect of newborn screening and management on thalassaemias	NBS-THAL
Effect of newborn screening and treatment on orofacial clefts	NBS-OFC
Effect of newborn screening and treatment on phenylketonuria	NBS-PKU
Effect of newborn screening and management on cystic fibrosis	NBS-CF

# United Kingdom Shared Data Demographic, maternal health and socio-economic indicators

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

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

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

Number of persons by age-group and sex		Estimates		Your estimates		Cho	sen estima	ates	
Age group	Male	Female	Total	Male	Female	Total	Male	Female	Total
0-4 years	1914659	1824525	3739184			0			0
5-9 years	1738670	1660728	3399398			0			0
10-14 years	1860462	1774098	3634560			0			0
15-19 years	2042124	1933594	3975718			0			0
20-24 years	2171520	2073161	4244681			0			0
25-29 years	2092161	2026269	4118430			0			0
30-34 years	1924431	1907355	3831786			0			0
35-39 years	2168170	2211137	4379307			0			0
40-44 years	2331089	2370075	4701164			0			0
45-49 years	2168397	2237779	4406176			0			0
50-54 years	1902978	1946889	3849867			0			0
55-59 years	1777643	1837527	3615170			0			0
60-64 years	1799069	1881165	3680234			0			0
65+ years	4372548	5646868	10019416			0			0
Total	0	0	61595091	0	0	0	0	0	0
Female population aged 15-44 years		0			0			0	
Data year		2009 report	ed in 2010						
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

	Estimate	Source, Year	Your	Source, Year	Chosen	Source,
Fertility and mortality			estimate		estimate	Year
Stindarhirtateats bive hirtbaths Bbby average at 90 000 putation	12	Unicef, 2007				
births	4	WHO, 2009				
Total births in 1000s (LB+SB) per year	722.00	Unicef, 2007				
Infant mortality rate: infant deaths / 1000 LB / year	5.00	UNICEF				
Under-5 mortality rate: U5 deaths / 1000 LB / year	5.00	(名Q11日度F2010				
Percentage births in women >35 years		(2011), 2010				
Life expectancy at birth (yrs)	80	WHO, 2009				
% of marriages consanguineous						

Maternal health	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Prenatal visits – at least 1 visit (%)						
Prenatal visits – at least 4 visits (%)						
Births attended by skilled health personnel (%)	99	WHO, 1998				
Contraception prevalence rate (%)	84.0	WHO, 2009				
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	Source, Year	Chosen estimate	
Gross national income per capita (PPP int. \$)	36240	WHO, 2008			
% population living on < US\$1 per day					
Birth registration coverage (%)	>90	WHO, 2007			
Death registration coverage (%)	90-100	WHO, 2009			

LB = live births

PPP = purchasing power parity

SBA = skilled birth attendant

PHG FOUNDATION

HealthServices

United Kingdom Shared Data Health Services Data

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

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

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

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

Health Expenditure	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Per capita total expenditure on health (PPP int. \$)	3399	WHO, 2009				
Total expenditure on health as percentage of GDP	9.3	WHO, 2009				
Per capita government expenditure on health (PPP int. \$)	2843	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	83.6	WHO, 2009				
Out-of-pocket expenditure as percentage of private expenditure on health	63.7	WHO, 2009				
Private expenditure on health as percentage of total expenditure on health	16.4	WHO, 2009				
General government expenditure on health as percentage of total government expenditure	15.1	WHO, 2009				

		Source,	Your	Source,	Chosen	Source,
Health Workforce	Estimate	Year	estimate	Year	estimate	Year
Number of nursing and midwifery personnel	621755	WHO, 2009				
Nursing and midwifery personnel density (per 10,000 population)	103	WHO, 2009				
Number of physicians	165317	WHO, 2009				
Physician density (per 10 000 population)	27.39	WHO, 2009				
Number of obstetricians						
Number of paediatricians						
Number of paediatric surgeons						
Number of paediatric cardiac surgeons						
Number of paediatric neurosurgeons						
Number of clinical geneticists						
Number of genetic counsellors						
Number of community health workers						
Number of skilled birth attendants (SBA)						
Density of SBA						

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

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

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

CD = congenital disorders

## United Kingdom

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 sub- national level	Condition prevalence per 1000 newborns	Prevalence variation and high-risk populations
Eye problems					
Signs of heart disease					
Developmental dysplasia of hips					
Genital anomalies (e.g. un- descended testicles)					
Orofacial clefts					
Dysmorphologies					
Hearing loss					
Congenital hypothyroidism					
G6PD deficiency					
PKU					
Cystic fibrosis					
Thalassaemias					
Sickle cell disease					
MCADD					
САН					
Other					

NBS = newborn screening

G6PD = glucose-6-phosphate dehydrogenase

PKU = phenylketonuria

CAH= congenital adrenal hyperplasia

MCADD = medium-chain acyl-CoA dehydrogenase deficiency

### United Kingdom 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 coverage (%)
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	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

\* As defined in the Background document section titled Newborn Screening Tests

# United Kingdom 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

\* 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 uncontrolled cases of CHT X Baseline birth prevalence)

#### United Kingdom Newborn screening Effects of NBS and treatment on G6PD deficiency

		1
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

\* 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 uncontrolled cases of G6PD X Baseline birth prevalence)

## United Kingdom 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

\* 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 uncontrolled cases of RHD X Baseline birth prevalence)

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

Baseline birth prevalence of sickle cell disease, per 1000 LB		
Variables		
Proversion of the source of th		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

\* 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 SCD X Baseline birth prevalence)

## United Kingdom 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)

#### United Kingdom 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

\* 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 untreated cases of OFC X Baseline birth prevalence)

#### United Kingdom 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

\* 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 prevalence of clinical cases of PKU X Baseline birth prevalence)

## United Kingdom Newborn screening Effects of NBS and management on cystic fibrosis

Baseline birth prevalence of cycstic fibrosis, per 1000 LB		
Variables		
PRYSTAIGN STREAMER SCIEBNER 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)