PHG Needs Assessment Calculator United Kingdom Sickle Cell Disease

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

(There is no sheet SCD-NA2.)

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		Yo	ur estimat	es	Cho	sen estim	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			-			-	
Data year		2009 report	ted 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

Fertility and mortality	Estimate	Source, Year	Your estimate	Source, Year	Chosen estimate	Source, Year
Crude birth rate: live births (LB) / year / 1000 population	12	Unicef, 2007				
Still birth rate: still births (SB) / year / 1000 total births	4	WHO, 2009				
Total births in 1000s (LB+SB) per year	722	Unicef, 2007				
Infant mortality rate: infant deaths / 1000 LB / year	5	UNICEF				
Under-5 mortality rate: U5 deaths / 1000 LB / year	5	(2)10位度月2010				
Percentage births in women >35 years		(2011), 2010				
Life expectancy at birth (yrs)	80	WHO, 2009				
% of marriages consanguineous						

	Estimate	Source, Year	Your	Source,	Chosen	Source,
Maternal health			estimate	Year	estimate	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						
	Estimate	Source, Year	Your	Source,	Chosen	Source,
Newborn health			estimate	Year	estimate	Year
Number of neonatal examinations by SBA / trained staff						
% neonatal examinations by SBA/ trained staff						

					Chosen	Source,
Socio-economic indicators	Estimate	Source, Year	estimate	Year	estimate	Year
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

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			

		Source,	Your	Source,	Chosen	Source,
Infrastructure	Estimate	Year	estimate	Year	estimate	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

SCD 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 (/100	0)					
Live birth prevalence (LB)			0.24			
Stillbirth prevalence (SB)			0.00			
Total birth prevalence (LB+SB)			0.27			
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			160			
All age groups						
<1 year olds						
1-4 year olds						
5-14 year olds						
15-44 year olds						
45+ year olds						
% cases by level of impairment						
No or minor disability			30.2			
Moderate disability*			50.0			
Severe disability*			19.8			
Mortality and morbidity						
Mean life expectancy (yrs)						
No. deaths < 1yr			4			
No. deaths 1-4 yrs			1			
No. deaths < 5 yrs			5			
Infant mortality / 1000 LB			0.01			
Under-5 mortality / 1000 LB			0.01			
Years of life lost						

LB = live births; SB = stillbirths * Moderate = 6-15% HbA present; Severe = 1-5% HbA present

United Kingdom Sickle Cell Disease

SCD Epidemiology 1.2: International comparison

	Your chosen		Comparison	
Epidemiological indicator	estimates	Country	Region	World
Prevalence at birth and by age-group (/1000 p	eople)		(Europe, Western)	
Live birth prevalence (LB)		0.24	0.10	2.70
Stillbirth prevalence (SB)		0.00	0.00	0.00
Total birth prevalence (LB+SB)		0.27	0.10	2.70
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		160	402	358127
All age groups			0	0
<1 year olds			0	0
1-4 year olds			0	0
5-14 year olds			0	0
15-44 year olds			0	0
45+ year olds			0	0
% cases by level of impairment				
No or minor disability		30.2	16.56	11.74
Moderate disability		50.0	50.00	50.00
Severe disability*		19.8	33.44	38.26
Mortality and morbidity				
Mean life expectancy (yrs)				
No. deaths < 1yr		4	10	168737
No. deaths 1-4 yrs		1	3	42184
No. deaths < 5 yrs		5	13	210921
Infant mortality / 1000 LB		0.01	0.00	1.27
Under-5 mortality / 1000 LB		0.01	0.00	1.59
Years of life lost				

LB = live births; SB = stillbirths * Moderate = 6-15% HbA present; Severe = 1-5% HbA present

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

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

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

SCD Epidemiology 2.2: Data on affected pregnancies: Surveillance

Based on surveillance data, enter the best estimates for the prevalence of the condition in live births and stillbirths. 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	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			

SCD 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			
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 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!	

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).

Number of affected live births	LB prevalence / 1000 TB
Number of affected still births	SB prevalence / 1000 TB
	live births Number of affected

SCD Epidemiology 2.4: Summary of affected pregnancies

Indicator	Your estimates	Range	PHGDB minimum estimates	Chosen estimates	Range	Source
Number of annual affected live births			160			
Annual birth prevalence / 1000 TB			0.24]
Number of annual affected still births			0			
Annual Stillbirth prevalence / 1000 TB			0.00			

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.

SCD 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

SCD 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

SCD 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.

	Range: 0 to 1
	Range: 0 to 1
0	
#DIV/0!	
#DIV/0!	
#DIV/0!	
#DIV/0!	
#DIV/0!	
#DIV/0!	
#DIV/0!	
	#DIV/0! #DIV/0! #DIV/0! #DIV/0! #DIV/0!

SCD Epidemiology 3.3: Mortality data: Other sources

So	ource, 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 morta	lity	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						

SCD 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)			663			
Number of annual affected neonatal deaths			0			
Number of affected neonatal deaths / 1000 LB			0.00			
Number of annual affected infant deaths			4			
Number of affected infant deaths / 1000 LB			0.01			
Number of annual affected under-5 deaths			5			
Number of affected under-5 deaths / 1000 LB			0.01			
Mean life expectancy at birth in affected people						
Other indicators (e.g. survival following surgical procedure, etc)						

SCD 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	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 affected persons	Cause-specific, group-specific mortality ratio / 1000 population	Reason for variation
Population sub-group	anected persons	mortality ratio / root population	
		+	

SCD 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			

SCD 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			

SCD 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				

SCD 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)

SCD Intervention 1: Effects of NBS and management on sickle cell disease

	Range: 0 to 1
	Range: 0 to 1
	Range: 0 to 1
0	
0	

LB = live births

SCD = sickle cell disease

NBS = newborn screening

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

²Baseline birth prevalence – (Proportional reduction of unmanaged cases of SCD X Baseline birth prevalence)

^{*} 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).

United Kingdom
Sickle Cell Disease
SCD Needs Assessment 1: Quantitative baseline

Table SCD-NA1a Burden of Sickle Cell Disease in pregnancy, at birth and at population level

	Chosen estimates			Notes
Indicator	Number (n)		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 SCD-NA1b Sickle Cell Disease mortality indicators

	Chosen estimates			Notes
Indicator	Number (n)		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

SCD Needs Assessment 3: Quantitative assessment of interventions

Table SCD-NA3a	Estimated prevalence in the absence of interventions for Sickle Cell Disease		
Indicator	Number (n)	Prevalence (n/1000)	
Potential live births			
Potential still births			

Table SCD-NA3b	Current situation in relation to interventions before birth			
Intervention	Coverage (%)	Cases averted (n)	Cases averted/1000 LB	
Effect of family planning, education				
Effect of population carrier screening				
Effect of preconception screening				
Effect of prenatal screening				
Effect of prenatal diagnosis				
Overall effect				

Table SCD-NA3c	Target situation in relation to interventions before birth		
Intervention	Coverage (%)	Cases averted (n)	Cases averted/1000 LB
Effect of family planning, education			
Effect of population carrier screening			
Effect of preconception screening			
Effect of prenatal screening			
Effect of prenatal diagnosis			
Overall effect			

Table SCD-NA3d	Current situation in relation to interventions after birth			
Intervention	Coverage (%)	Cases managed (n)	Cases managed/1000 LB	
Effect of newborn diagnosis				
Effect of blood transfusion				
Effect of infection prevention				
Effect of iron chelation				
Effect of social care and support				
Overall effect				

Table SCD-NA3e	Target situation in relation to interventions after birth			
Intervention	Coverage (%)	Cases managed (n)	Cases managed/1000 LB	
Effect of newborn diagnosis				
Effect of blood transfusion				
Effect of infection prevention				
Effect of iron chelation				
Effect of social care and support				
Overall effect				

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