



# Introduction to HNA and Toolkit Methodology

**Part of the PHG Foundation Toolkit  
for Assessing Health Needs in rela-  
tion to Congenital Disorders**

Version 1.1: September 2013

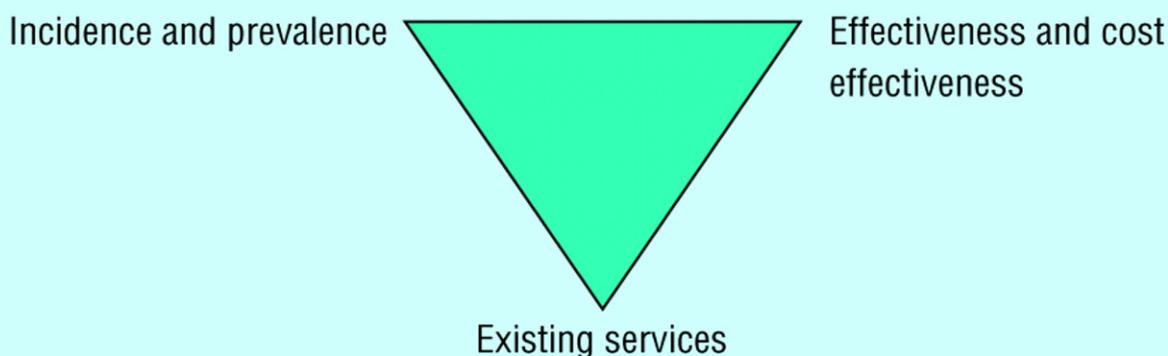
# Introduction to health needs assessment

Health needs assessment (HNA) is a systematic method aimed at identifying unmet health needs in a population and making changes in response<sup>1,2</sup> (Box 1). Health care need relates to the ability of the population to benefit from (health care) interventions or services. Health needs also include the ability to benefit from changes to the frequency and distribution of risk factors, and of social and environmental factors that influence health, e.g. socioeconomic status, education, diet, employment and behaviour.

Need relates to the occurrence and severity of the problem under consideration, the effectiveness and cost-effectiveness of interventions addressing the problem, and the availability of and access to services and interventions by those who need them. Identifying (and then addressing) inequalities in determinants of health and services are important components of the HNA.

## Box 1. Health Needs Assessment

*Process to identify health needs and inequalities in a population, leading to agreed priorities and resource allocation that will improve health and reduce inequalities*



Source: Williams and Wright, BMJ 1998

There are a number of approaches that are combined in a needs assessment<sup>3</sup>, with the approach pictured in Box 1 termed the epidemiological approach and is based on combining knowledge of incidence and prevalence with assessment of effectiveness of interventions. Although the epidemiological approach is comprehensive, additional approaches can be used when epidemiological data is lacking or resources to review such information are unavailable. These can involve comparison of level of service between populations in different areas (comparative) or consideration of the views of different interested parties from politicians to patients. Although these later two approaches may be used by themselves, they are often useful supplements to the epidemiological approach as they allow a fuller assessment.

<sup>1</sup> Wright J, Williams R and Wilkinson JR (1998) *Development and importance of health needs assessment*, BMJ: 25; 316(7140):1310-3.

<sup>2</sup> Williams R and Wright J (1998) *Epidemiological issues in health needs assessment* BMJ: 2; 316(7141):1379-82.

<sup>3</sup> Stevens A and Raftery J (ed) (1997), *Health care needs assessment (2<sup>nd</sup> series)*, Radcliffe Medical Press oxford

A combination of the three Health Needs Assessment (HNA) approaches described above used in the context of congenital disorders, is the basic framework used in this Toolkit and underpin the process and actions potentially resulting from it. The Toolkit is the ‘instrument’ that enables users to conduct the HNA in a structured way, focusing on identifying gaps in service provision and the steps needed to prioritise, plan, implement and evaluate health actions to narrow these gaps. The Toolkit does this by guiding users through the needs assessment process and allowing them to collate the following:

- Demographic data on the country or region
- Key epidemiological indicators for the burden of disease for a chosen condition or conditions, and the potential effects of specific interventions
- A structured assessment of existing policies, programmes, services and interventions in terms of their availability, quality, coverage and effectiveness
- A comparison of the current situation (“where are we now?”) with the desired situation (“where do we want to be?”)
- Identified gaps and unmet needs
- Qualitative assessments of the effectiveness of interventions
- Prioritised action areas and interventions that are relevant and appropriate to the level of socio-economic development of the country and are sensitive to societal values, culture and legislation.

The HNA process stresses the importance of involving all major stakeholder groups including, for example, policy makers, government/ministry representatives, public health and clinical professionals from a range of health services, laboratory scientists, representatives from patient support groups and charities, health economists, researchers and the private health sector. This inclusive approach maximises the chances that the project’s conclusions will have broad acceptance and that effective action will follow.

# Toolkit Methodology

## Scope of the Toolkit

The rationale for developing this Toolkit is provided in the *Overview Document to the PHG Foundation Toolkit for Assessing Health Needs in Relation to Congenital Disorders*. Based on this rationale a number of topics were selected for inclusion in the Toolkit and are listed in Table 1; they have been split into two categories, clinical and service. Topics not currently included within the Toolkit can be created although they may lack estimated/modelled data on the burden of disease. However, it should be noted that the topics listed below are considered to be official versions and any topics created by the user community itself do not automatically become official versions.

**Table 1:** Topics currently included in the Toolkit

Clinical (listed alphabetically)	Service (listed alphabetically)
Congenital heart disease	Health services
Congenital hypothyroidism	Newborn screening
Congenital rubella syndrome	Preconception care and screening
Congenital syphilis	Prenatal services
Down's syndrome	Teratogens
Fetal alcohol spectrum disorder	
Glucose-6-phosphate dehydrogenase deficiency	
Neural tube defects	
Orofacial clefts	
Rhesus D haemolytic disease of the newborn	
Sickle cell disease	
Thalassaemias	

## Method of development

The Toolkit was developed over a period of two years by the PHG Foundation with support from the Centre for Health Informatics and Multiprofessional Education (CHIME) at University College London, with direction from a small steering group (Appendix 1). A number of external experts have also contributed to individual topics by authoring specific sections or acting as reviewers. A full list of the project contributors can be found in Appendix 2.

During 2010, a prototype was piloted by three countries in Latin America: Argentina, Uruguay and Brazil and some of the Toolkit materials were also subsequently evaluated in an international workshop in June 2011.

## The Toolkit

The PHG Foundation Needs Assessment Toolkit consists of several components that can assist in conducting a needs assessment. Documents are included that contain general information based on a review of the literature and serve to give introductions to specific topics or in relation to specific subjects such as consanguinity, ethical, legal and social issues in relation to congenital disorders, multi-criteria decision analysis and patient engagement.

Each topic contains a background document that provides information and data on the epidemiology of specific conditions (such as risk factors, burden of morbidity and mortality), with an emphasis on public health approaches to their control at population level. We have also attempted to provide some information on effectiveness and cost-effectiveness based on a review of the literature; however this is not extensive. It is also important to bear in mind that the costs and impact of interventions vary depending on local circumstances, including the level of development and mode of organisation of health and other services, availability of local resources and technology, and societal values.

The Toolkit also provides guidance on the evaluation of existing services and interventions, identification of gaps and how these may be addressed. The evaluation is based on commonly used frameworks<sup>4</sup> and considers existing resources or structures (e.g. finances, facilities, equipment and trained personnel), processes and outputs (measures of activity such as clinics run, preconception visits undertaken, coverage of screening and treatment services) and outcomes, i.e. related to the occurrence, morbidity and mortality from congenital disorders. Quality is an important domain within the evaluation of services and includes measures such as effectiveness, efficiency, equity, accessibility, acceptability and responsiveness. The Guide document provides an overview of the process and how the various documents for each topic are intended to be used.

As part of the Toolkit, we provide a range of demographic, health services and epidemiological data that are relevant at global, regional and national levels. More information on the sources of this data is given in the next section. Most of the epidemiological and effectiveness data are derived from mathematical models and are subject to varying degrees of uncertainty, depending on the type of data and where it applies to, i.e. which country or region<sup>5</sup>. For this reason we suggest that the use of local data (where available) may be preferable, although it may need to be adjusted to account for limitations in quality and representativeness.

We also provide epidemiological estimates for certain congenital disorders; these are derived from the Modell Database of Constitutional Congenital Disorders (MGDB), developed by Professor Bernadette Modell and colleagues from CHIME for selected congenital disorders. More details on the MGDB can be found in the next section. Of note, not all topics include estimated/modelled data but instead require data to be collected or estimated by Toolkit users. The data that are included are by no means intended to be definitive and should only be used as a starting point.

The official language used within the Toolkit is English (UK). We are aware that not everybody can understand English and are looking at how best to provide translated versions of the Toolkit. However, it should be noted that the official version is the English language version and that a translated copy would be an accompaniment to the official document and not an official version itself.

---

<sup>4</sup> Donabedian A (1978) *The quality of medical care*. Science; 200:856-64.

<sup>5</sup> The demographic and health services data we provide come from international sources, which although usually based on data provided by the countries, may in some instances not represent the most up-to-date information available at country level.

## Introduction to PHG DataBase (PHGDB)

PHGDB is the database that the PHG Foundation has compiled in order to help support the data needs of the Toolkit to address the first two steps of the HNA process as outlined above i.e. demographic data and key epidemiological indicators. The data within PHGDB are only intended to be used as starting points with Toolkit users urged to source local up-to-date data. The data within PHGDB will be periodically revisited in order to update data sources or add new data that is relevant for the Toolkit.

### What countries are included?

ISO codes for the countries included within this version of the Toolkit were taken from the International Organization for Standardization website ([http://www.iso.org/iso/country\\_codes/iso\\_3166\\_code\\_lists/country\\_names\\_and\\_code\\_elements.htm](http://www.iso.org/iso/country_codes/iso_3166_code_lists/country_names_and_code_elements.htm)) and are the ISO 3166-1-alpha-2 code elements.

A list of countries included in the Toolkit can be found in Appendix 3. Countries not currently included within the Toolkit can be added although they may lack estimated/modelled data.

### How are international comparisons made?

PHGDB uses the same geographic regions (21 distinct regions) as the Global Burden of Diseases (GBD) Study (Chapter 8 [http://www.globalburden.org/GBD\\_Study\\_Operations\\_Manual\\_Jan\\_20\\_2009.pdf](http://www.globalburden.org/GBD_Study_Operations_Manual_Jan_20_2009.pdf)) in order to allow international or regional comparison if required. See Appendix 4.

### Where do demographic profiles come from?

Demographic profiles have been compiled for each of the countries included within the Toolkit. Demography data were downloaded from the United Nations Statistics Division Demographic statistics website (<http://unstats.un.org/unsd/demographic/default.htm>) and UN Demographic Yearbook (<http://unstats.un.org/unsd/demographic/products/dyb/dyb2.htm>). We took the pragmatic decision to group the demographic population pyramid into 14 age-intervals of 5 years for male, female and total population (see Appendix 5). This worked well logistically as the data was presented this way as a minimum by the UN website. In some instances the data were found in single year intervals in which case they were grouped into the 5 year intervals by summing the appropriate years. Because these data are sometimes estimated with figures rounded to the nearest whole number for each age group used, the national totals are often different from the sum of the individual age groups because of these rounding errors.

Another problem encountered was that these data are not always up-to-date and are often quite old, so if the age-stratified data are added to give national totals, the results are different from the estimated national totals available for more recent years. National totals not stratified by age-intervals or sex are also available from the UN Demographic Yearbook and as such are often different to the available stratified data. We acknowledge these limitations and urge users to enter their own more up-to-date and complete data where possible. Our aim was to use a single source to gain as much data as possible in order to allow comparability across countries. The UN Demographic Yearbook is an annual compendium of official statistics that have been collected from national statistics authorities from over 230 national offices since 1948 by using a set of questionnaires. Inclusion of up-to-date information for each country is dependent on each of the national offices returning the questionnaires.

Also included in the Demography section of the Toolkit are estimates on fertility and mortality, maternal health, newborn health, and some socio-economic variables. The data within these sections can be patchy depending on what is available from WHO Global Health Observatory World Health Statistics and Health Systems (<http://apps.who.int/ghodata/>), the United Nations Statistics Division (<http://unstats.un.org/unsd/databases.htm>), the Consanguinity/Endogamy resource maintained by Professor Alan Bittles ([http://consang.net/index.php/Main\\_Page](http://consang.net/index.php/Main_Page)), and Unicef for under-five, infant, and neonatal mortality ([http://www.childinfo.org/mortality\\_tables.php](http://www.childinfo.org/mortality_tables.php) along with a report on estimates developed by the UN Inter-agency group for child mortality estimation [http://www.unicef.org/media/files/Child\\_Mortality\\_Report\\_2011\\_Final.pdf](http://www.unicef.org/media/files/Child_Mortality_Report_2011_Final.pdf)).

The WHO have a disclaimer which states that many of their databases represent the best estimates of WHO using methodologies for specific indicators that aim for comparability across countries and time and that they are updated either as more recent or revised data becomes available or the methodology used to calculate the data changes. They also state that their data is not always the same as that from Official Nationals but they do give their Member States the opportunity to review and comment on the data and estimates as part of country consultations.

### **Fertility and mortality**

The fertility and mortality section includes estimates on: crude birth rate (births per year per 1,000 population); still birth rate (still births per year per 1,000 population); total births per year (number of live births and still births); infant mortality rate (infant deaths – i.e. aged 1 year or under – per 1,000 live births per year); under-5 mortality rate (under-5 deaths – i.e. aged 5 or under – per 1,000 live births per year); percentage births in women over the age of 35 years; average life expectancy at birth (in years); percentage of marriages that are consanguineous, noting the data limitations in representativeness and on how up-to-date the data are.

### **Maternal health**

The maternal health section includes estimates on: percentage of pregnancies with at least one prenatal visit; percentage of pregnancies with at least four prenatal visits; percentage of births attended by a skilled health professional; the contraception prevalence rate (percentage of women between 15 and 49 years of age who are practising, or have sexual partners who are practising, any form of contraception); percentage unmet need for family planning (is the number of women with unmet need for family planning as a percentage of all women of reproductive age who are married or in a union); total fertility rate (is the average number of children that would be born per woman over her lifetime if that woman followed the current age-specific fertility rates and lived to at least the end of her reproductive life); percentage of births occurring at home; percentage of births occurring at health care facilities or services.

### **Newborn health**

The newborn health section includes estimates on: the number of neonatal (within the first 28 days or month after birth) examinations conducted by skilled birth attendants or trained staff; the percentage of neonatal examinations conducted by skilled birth attendants or trained staff.

## Socio-economic indicators

The socio-economic indicators section includes estimates on: the gross national income per capita PPP int. \$ (this is the gross national income per capita converted to international dollars using purchasing power parity (PPP) rates so that an international dollar has the same purchasing power as a US dollar has in the USA); percentage of the population living on less than US\$1 per day (a commonly used international poverty indicator); percentage of births in a given year that are officially registered; percentage of deaths in a given year that are officially registered.

## Where do health services data come from?

Health services data profiles have been compiled for each of the countries included within the Toolkit and include estimates on health expenditure, health workforce, and infrastructure. The data within these sections is patchy depending on what is available from WHO Global Health Observatory World Health Statistics and Health Systems (<http://apps.who.int/ghodata/>) and the United Nations Statistics Division (<http://unstats.un.org/unsd/databases.htm>). Despite gaps in the data provided, the health workforce and infrastructure data are clearly important and efforts should be made to obtain local data.

## Health expenditure

The health expenditure section includes estimates on: total expenditure on health per capita purchasing power parity (PPP) Int. \$ (purchasing power parity rates are used so that one Int. \$ has the same purchasing power as one US \$ in the US); total expenditure on health as a percentage of the gross domestic product; government expenditure on health per capita PPP Int. \$; external resources for health as a percentage of the total expenditure on health; general government expenditure on health as a percentage of the total expenditure on health; out-of-pocket expenditure on health as a percentage of private expenditure on health; private expenditure on health as a percentage of total expenditure on health; general government expenditure on health as a percentage of total government expenditure.

## Health workforce

The health workforce section includes some estimates on: number of nursing and midwifery personnel; density per 10,000 population of nursing and midwifery personnel; number of physicians/doctors; density per 10,000 population of physicians/doctors; 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 care workers; number of skilled birth attendants; density per 10,000 women of reproductive age (15 to 49 years of age) of skilled birth attendants; number of laboratory staff providing cytogenetic testing; number of lab staff providing molecular genetics testing; number of lab staff providing biochemical tests for genetics; number of skilled health attendants/workers.

## Infrastructure

The infrastructure section has the following indicators: number of maternity units; number of services providing specialised care for people with congenital disorders; number of family planning services; number of preconception services; number of services providing prenatal care; number of services providing newborn or neonatal care; number of facilities providing genetic services; number of labs providing cytogenetic services; number of laboratories

providing molecular genetic services; number of laboratories providing biochemical tests for genetics; number of facilities offering terminations of pregnancies for fetal defects.

### Where does the condition-specific epidemiology come from?

Currently there are two sources of global epidemiological data in relation to congenital disorders: the Global Burden of Disease (GBD) study and the Modell Database of Constitutional Congenital Disorders (MGDB). There is overlap in the contributors to MGDB and GBD, however, the final inputs and outputs produced differ due to differences in the methodological approaches taken.

In December 2012 the latest GBD update (GBD2010) was published, presenting high level methods and results for 291 conditions throughout the whole human lifespan at a global level. The GBD cause list includes congenital anomalies (neural tube defects, congenital heart anomalies, cleft lip and cleft palate, Down's syndrome, other chromosomal anomalies and other congenital anomalies).

The top-level summary findings of the Global Burden of Disease (GBD) study 2010 are available in the form of seven articles published in the Lancet as well as regional information via the Institute of Health Metrics and Evaluation (IHME) website. These articles and associated datasets provide data on different aspects of the study (including data for different countries and world regions, men and women, and different age groups), specifically relating to Disability adjusted life year (DALYs), Years of Life Lost (YLL), Years Lost due to Disability (YLD) and cause of death. However, detailed information relating to country-specific prevalence is not yet available.

The summary data from the GBD study are only minimally useful to PHGDB. This is because they only give regional estimates and metrics for YLL, YLD and DALYs. PHGDB requires more detailed information such as country level data relating to prevalence of specific congenital disorders, prevalence within specific age groups, life expectancy of those with the condition etc. As this information is available via MGDB, it was decided to use this data source within the Toolkit for condition-specific epidemiology.

Modell Database of Constitutional Disorders (MGDB)

The MGDB was developed by Professor Bernadette Modell in response to the scarcity of national and global data in relation to congenital disorders. The estimates present in PHGDB are based on data from the 2012 updated version of the MGDB. Earlier versions of this database have been used by several publications including the *March of Dimes Global Report on Birth Defects*<sup>6</sup> and as a basis for work by Professor Arnold Christianson on genetics in developing countries<sup>7</sup>. The MGDB also forms the basis of the Global Burden of Disease estimates for congenital disorders (<http://www.globalburden.org/>).

The MGDB gives estimates for 2010 by country, for the purposes of the Toolkit these have also been bundled into GBDregional data:

- Potential births

This estimate is for the rate of potential births in the absence of any intervention. These estimates were obtained using information available from dedicated epidemiological studies,

<sup>6</sup> Christianson A, Howson CP, Modell B March of Dimes global report on birth defects. The hidden toll of dying and disabled children. March of Dimes Birth Defects Foundation. 2006. White Plains, New York.

<sup>7</sup> Christianson A, Modell B Annu Rev Genomics Hum Genet 2004 5:219-65.

established birth prevalence surveillance systems and registries together with demographic information from a number of UN sources. For countries where data was lacking, birth prevalence data from neighbouring or similar countries were used to make informed estimates. These base-line estimates were adjusted taking into account country-specific factors that would influence the prevalence of specific congenital disorders; these include carrier rates for recessive conditions, prevalence of consanguineous marriage and maternal age distribution.

- Outcomes of affected pregnancies (stillbirth, ToP, live birth)

Estimates of stillbirths were made based on the approximate stillbirth rate associated with selected disorders. For chromosomal disorders, neural tube defects and congenital heart disease the stillbirth rate was derived from EUROCAT data by calculating the proportion of continuing pregnancies that ended in fetal death.

The rates for termination of pregnancy are given for conditions where this might be applicable e.g. Downs syndrome and neural tube defects. (For conditions such as uncomplicated orofacial clefts termination rates are not included.) Termination rates are based on data on termination for fetal abnormality available from registers that participate in EUROCAT and ICBDSR where available, with adjustments for under-ascertainment as appropriate. Near-neighbour assumptions are made for 58 small countries without participating registers, out of 88 countries where termination of pregnancy is permitted. However, important information gaps remain for many countries where prenatal diagnosis is available. For China, estimation of terminations was derived from the sex ratios (assuming termination in female fetus to be of the same magnitude as those for malformations or anomalies), with estimates for countries such as India, Turkey and Egypt considered to be of similar magnitude, e.g. 10% termination for anencephaly and 5% termination for spina bifida.

For countries where termination for fetal abnormalities is illegal (96 countries at the time of writing), it is assumed that no terminations for fetal abnormality take place, although some are almost certainly done for malformations.

The estimated (total) birth prevalence is derived from potential births minus births avoided due to interventions before or during pregnancy, such as folic acid fortification of foods for neural tube defects and orofacial clefts, and pregnancy terminations. Information relating to prevention strategies was obtained from literature searches and their minimum estimated effect calculated.

The estimated live birth prevalence is calculated by subtracting estimated stillbirth prevalence from actual total birth prevalence.

- Mortality

Mortality due to congenital disorders was calculated taking into consideration prospective survival curves and the proportion of the population that has access to health services. Prospective survival curves were created for different settings based on mortality data up to five years of age, information from the literature on long-term survival related to specific conditions, expert opinion and in some cases data from charities collecting relevant data. Due to the lack of observational data on survival past 30-35 years of age, the observed mortality in the oldest 5-year age groups was extrapolated up to 70-80 years of age. Survival in the absence of diagnosis and interventions for many low-income countries was estimated using data from high-income countries that describe the baseline situation before the introduction of new interventions.

- Numbers and age distribution of those living with the disorder

The number of patients living with a disorder in a designated year was estimated by integrating available data for the following for each country and disorder:

1. Birth prevalence
2. Population age distribution, as obtained from UNDY where available (72% of countries in the world), with missing data on 5-year population distribution attributed using the distribution for nearest neighbour with age-group disaggregated data
3. History of utilisation of prenatal diagnosis services for the disorder
4. Retrospective survival curves for the disorder in different settings, which takes into account if and when a treatment policy was introduced, for all or part of the population

Data from the MGDB are used to provide epidemiological estimates for certain congenital disorders that are included in the PHG Foundation Needs Assessment Toolkit (See Table 2 below). It must be borne in mind that is an epidemiologically-modelled solution with conservative and minimum estimates made where possible and clinically meaningful. However as with all model-derived estimates a number of assumptions have been made and many of the calculations are based on best available data sets found within the published or unpublished literature. Every opportunity is provided for Toolkit users, where able, to use their own data. A more detailed description of how MGDB calculates disease-specific epidemiology can be found in the Supporting Document section on MGDB.

**Table 2:** Currently available data included in the Toolkit

Clinical (listed alphabetically)	Availability of epidemiological data from MGDB
Congenital heart disease	Yes
Congenital hypothyroidism and iodine deficiency disorder	Yes (does not include CHT caused by iodine deficiency)
Congenital rubella syndrome*	No
Congenital syphilis*	No
Down's syndrome	Yes
Teratogens	No
Fetal alcohol spectrum disorder	No
Glucose-6-phosphate dehydrogenase deficiency	Yes
Neural tube defects	Yes
Orofacial clefts	Yes
Rhesus D haemolytic disease of the newborn	Yes
Sickle cell disease	Yes
Thalassaemias	Yes

\*Limited data are available from WHO (see below)

### Other sources of epidemiological data

Where condition specific epidemiological data was unavailable, attempts were made to gather data that could be used as a proxy indicator. The data within these sections is patchy

depending on what is available from WHO, and should be interpreted with caution, as the reporting and surveillance methods in countries may vary.

For congenital rubella syndrome, data included in PHGDB are reported incidence of rubella and immunisation coverage. The data in PHGDB are for 2011 and were obtained from the WHO vaccine-preventable diseases: monitoring system 2012 global summary<sup>8</sup>.

For congenital syphilis, data included in PHGDB are reported proportion of women attending antenatal care, the proportion of women tested for syphilis at first visit and women attending antenatal care seropositive for syphilis. These data are from the 2011 progress report: Global HIV/AIDS response: epidemic update and health sector progress towards universal access: progress report 2011<sup>9</sup>.

---

<sup>8</sup> [http://apps.who.int/immunization\\_monitoring/en/globalsummary/timeseries/tsincidencedip.htm](http://apps.who.int/immunization_monitoring/en/globalsummary/timeseries/tsincidencedip.htm)

<sup>9</sup> [http://www.who.int/reproductivehealth/topics/rtis/GlobalData\\_cs\\_pregnancy2011.pdf](http://www.who.int/reproductivehealth/topics/rtis/GlobalData_cs_pregnancy2011.pdf)

## Appendix 1: Steering Group

Prof. Alan Bittles	(Edith Cowan University, Australia)
Dr Hilary Burton	(PHG Foundation, UK)
Prof. Arnold Christianson	(University of the Witwatersrand, South Africa)
Ms Patricia Gomez	(Jhpiego, US)
Dr Chris Howson	(March of Dimes, US)
Mr Alastair Kent	(Genetic Alliance, UK)
Prof. Betty Kirkwood	(London School of Hygiene & Tropical Medicine, UK)
Dr Elizabeth Mason	(World Health Organisation)
Prof. Bernadette Modell	(WHO Collaborating Centre, UCL CHIME, UK)
Prof. Irmgard Nippert	(University of Münster, Germany)
Mr Ysbrand Poortman	(Preparing for Life Initiative, Netherlands)
Prof. Lavinia Schuler-Faccini	(Universidade Federal do Rio Grande do Sul, Brazil)
Dr Peter Turnpenny	(Royal Devon & Exeter Hospital, UK)
Dr Severin von Xylander	(World Health Organisation)

## Appendix 2: List of project participants

### PHG Foundation

Ms Corinna Alberg  
Dr Hilary Burton  
Dr Susmita Chowdhury  
Ms Alison Hall  
Dr Sowmiya Moorthie  
Dr Luis Nacul  
Dr Nora Pashayan  
Dr Anna Pokorska-Bocci  
Dr Gurdeep Sagoo  
Dr Alison Stewart

### Additional Contributors

Dr Cristina Barreiro	Hospital de Pediatría Garrahan, Argentina
Dr Maria Paz Bidondo	Hospital de Pediatría Garrahan, Argentina
Prof. Alan Bittles	Edith Cowan University, Australia
Mr Craig Brooks-Rooney	Costello Medical Consulting, UK
Prof. Arnold Christianson	University of the Witwatersrand, South Africa
Prof. Antoinette Ciliers	C.H. Baragwanath Hospital, South Africa
Ms Sophie Costello	Costello Medical Consulting, UK
Dr Natasha Crowcroft	University of Toronto, Canada
Dr Matthew Darlison	WHO Collaborating Centre, UCL CHIME, UK
Dr Denhard de Smit	MediClara, Netherlands
Prof. Jack Dowie	London School of Hygiene & Tropical Medicine, UK
Dr Victoria Fearne	NHS Suffolk, UK
Prof. Suzanne Filteau	London School of Hygiene & Tropical Medicine, UK
Dr Richard Fordham	University of East Anglia, UK
Prof. Roberto Giugliani	WHO Collaborating Centre for the Development of Medical Genetics Services in Latin America, Brazil
Dr Boris Groisman	Centro Nacional de Genética Médica, Argentina
Mr Christopher Grollman	London School of Hygiene & Tropical Medicine, UK
Ms Nia Hamer	Costello Medical Consulting, UK
Ms Laura Hamerslag	Costello Medical Consulting, UK
Ms Sophie Haynes	Costello Medical Consulting, UK
Dr Ebrahim Hoosen	Inkosi Albert Luthuli Central Hospital, South Africa
Dr Dafne Horovitz	Instituto Fernandes Figueira, Brazil
Ms Jeanette Kusel	Costello Medical Consulting, UK
Dr Mariela Larrandaburu	Ministry of Public Health, Uruguay
Ms Celine Lewis	Genetic Alliance, UK
Dr Rosa Liascovich	Centro Nacional de Genética Médica, Argentina
Prof. Bernadette Modell	WHO Collaborating Centre, UCL CHIME, UK
Prof. Peter Mossey	University of Dundee, UK
Ms Anjali Nagpal	London School of Hygiene & Tropical Medicine, UK
Prof. Victor Penchazadeh	Ministry of Health, Argentina
Dr Maria Teresa Sanseverino	Hospital de Clinicas de Porto Alegre, Brazil
Prof. Lavinia Schuler-Faccini	Universidade Federal do Rio Grande do Sul, Brazil
Dr Geordan Shannon	University of Cambridge, UK
Ms Beth Timm	Costello Medical Consulting, UK
Dr Ishwar Verma	Sir Ganga Ram Hospital, India

Prof. Denis Viljoen  
Dr Pamela White

Foundation for Alcohol Related Research, South Africa  
Statistics Canada, Canada

## Organisational Funders and Supporters

Costello Medical Consulting  
Mothercare Group Foundation  
PHG Foundation  
UCL Centre for Health Informatics and Multiprofessional Education  
Wellbeing of Women

## Appendix 3: List of countries included in this version of the Toolkit

- Afghanistan (ISO code AF)
- Albania (ISO code AL)
- Algeria (ISO code DZ)
- Andorra (ISO code AD)
- Angola (ISO code AO)
- Antigua and Barbuda (ISO code AG)
- Argentina (ISO code AR)
- Armenia (ISO code AM)
- Australia (ISO code AU)
- Austria (ISO code AT)
- Azerbaijan (ISO code AZ)
- Bahamas (ISO code BS)
- Bahrain (ISO code BH)
- Bangladesh (ISO code BD)
- Barbados (ISO code BB)
- Belarus (ISO code BY)
- Belgium (ISO code BE)
- Belize (ISO code BZ)
- Benin (ISO code BJ)
- Bhutan (ISO code BT)
- Bolivia (ISO code BO)
- Bosnia and Herzegovina (ISO code BA)
- Botswana (ISO code BW)
- Brazil (ISO code BR)
- Brunei Darussalam (ISO code BN)
- Bulgaria (ISO code BG)
- Burkina Faso (ISO code BF)
- Burundi (ISO code BI)
- Cambodia (ISO code KH)
- Cameroon (ISO code CM)
- Canada (ISO code CA)
- Cape Verde (ISO code CV)
- Central African Republic (ISO code CF)
- Chad (ISO code TD)
- Chile (ISO code CL)
- China (ISO code CN)
- Colombia (ISO code CO)
- Comoros (ISO code KM)
- Congo, Democratic Republic of (ISO code CD)
- Congo (ISO code CG)
- Cook Islands (ISO code CK)
- Costa Rica (ISO code CR)
- Côte d'Ivoire (ISO code CI)
- Croatia (ISO code HR)
- Cuba (ISO code CU)
- Cyprus (ISO code CY)
- Czech Republic (ISO code CZ)
- Denmark (ISO code DK)
- Djibouti (ISO code DJ)
- Dominica (ISO code DM)
- Dominican Republic (ISO code DO)
- Ecuador (ISO code EC)
- Egypt (ISO code EG)
- El Salvador (ISO code SV)
- Equatorial Guinea (ISO code GQ)
- Eritrea (ISO code ER)
- Estonia (ISO code EE)
- Ethiopia (ISO code ET)
- Fiji (ISO code FJ)
- Finland (ISO code FI)
- France (ISO code FR)
- Gabon (ISO code GA)

- Gambia (ISO code GM)
- Georgia (ISO code GE)
- Germany (ISO code DE)
- Ghana (ISO code GH)
- Greece (ISO code GR)
- Grenada (ISO code GD)
- Guatemala (ISO code GT)
- Guinea (ISO code GN)
- Guinea-Bissau (ISO code GW)
- Guyana (ISO code GY)
- Haiti (ISO code HT)
- Honduras (ISO code HN)
- Hong Kong (ISO code HK)
- Hungary (ISO code HU)
- Iceland (ISO code IS)
- India (ISO code IN)
- Indonesia (ISO code ID)
- Iran (ISO code IR)
- Iraq (ISO code IQ)
- Ireland (ISO code IE)
- Israel (ISO code IL)
- Italy (ISO code IT)
- Jamaica (ISO code JM)
- Japan (ISO code JP)
- Jordan (ISO code JO)
- Kazakhstan (ISO code KZ)
- Kenya (ISO code KE)
- Kiribati (ISO code KI)
- Korea, Democratic Peoples' Republic of (ISO code KP)
- Korea, Republic of (ISO code KR)
- Kuwait (ISO code KW)
- Kyrgyzstan (ISO code KG)
- Lao People's Democratic Republic (ISO code LA)
- Latvia (ISO code LV)
- Lebanon (ISO code LB)
- Lesotho (ISO code LS)
- Liberia (ISO code LR)
- Libyan Arab Jamahiriya (ISO code LY)
- Liechtenstein (ISO code LI)
- Lithuania (ISO code LT)
- Luxembourg (ISO code LU)
- Macedonia (ISO code MK)
- Madagascar (ISO code MG)
- Malawi (ISO code MW)
- Malaysia (ISO code MY)
- Maldives (ISO code MV)
- Mali (ISO code ML)
- Malta (ISO code MT)
- Marshall Islands (ISO code MH)
- Mauritania (ISO code MR)
- Mauritius (ISO code MU)
- Mexico (ISO code MX)
- Micronesia (ISO code FM)
- Moldova (ISO code MD)
- Monaco (ISO code MC)
- Mongolia (ISO code MN)
- Montenegro (ISO code ME)
- Morocco (ISO code MA)
- Mozambique (ISO code MZ)
- Myanmar (ISO code MM)
- Namibia (ISO code NA)
- Nauru (ISO code NR)
- Nepal (ISO code NP)
- Netherlands (ISO code NL)
- New Zealand (ISO code NZ)
- Nicaragua (ISO code NI)
- Niger (ISO code NE)
- Nigeria (ISO code NG)
- Niue (ISO code NU)

- Norway (ISO code NO)
- Oman (ISO code OM)
- Pakistan (ISO code PK)
- Palau (ISO code PW)
- Panama (ISO code PA)
- Papua New Guinea (ISO code PG)
- Paraguay (ISO code PY)
- Peru (ISO code PE)
- Philippines (ISO code PH)
- Poland (ISO code PL)
- Portugal (ISO code PT)
- Qatar (ISO code QA)
- Romania (ISO code RO)
- Russian Federation (ISO code RU)
- Rwanda (ISO code RW)
- Saint Kitts and Nevis (ISO code KN)
- Saint Lucia (ISO code LC)
- Saint Vincent and the Grenadines (ISO code VC)
- Samoa (ISO code WS)
- San Marino (ISO code SM)
- Sao Tome and Principe (ISO code ST)
- Saudi Arabia (ISO code SA)
- Senegal (ISO code SN)
- Serbia (ISO code RS)
- Seychelles (ISO code SC)
- Sierra Leone (ISO code SL)
- Singapore (ISO code SG)
- Slovakia (ISO code SK)
- Slovenia (ISO code SI)
- Solomon Islands (ISO code SB)
- Somalia (ISO code SO)
- South Africa (ISO code ZA)
- Spain (ISO code ES)
- Sri Lanka (ISO code LK)
- Sudan (ISO code SD)
- Suriname (ISO code SR)
- Swaziland (ISO code SZ)
- Sweden (ISO code SE)
- Switzerland (ISO code CH)
- Syrian Arab Republic (ISO code SY)
- Tajikistan (ISO code TJ)
- Tanzania (ISO code TZ)
- Thailand (ISO code TH)
- Timor-Leste (ISO code TP)
- Togo (ISO code TG)
- Tonga (ISO code TO)
- Trinidad and Tobago (ISO code TT)
- Tunisia (ISO code TN)
- Turkey (ISO code TR)
- Turkmenistan (ISO code TM)
- Tuvalu (ISO code TV)
- Uganda (ISO code UG)
- Ukraine (ISO code UA)
- United Arab Emirates (ISO code AE)
- United Kingdom (ISO code GB)
- United States of America (ISO code US)
- Uruguay (ISO code UY)
- Uzbekistan (ISO code UZ)
- Vanuatu (ISO code VU)
- Venezuela (ISO code VE)
- Viet Nam (ISO code VN)
- Yemen (ISO code YE)
- Zambia (ISO code ZM)
- Zimbabwe (ISO code ZW)

# Appendix 4: Countries included in the Toolkit listed by GBD region

## **Asia Pacific, High Income**

Brunei Darussalam, Japan, Republic of Korea, Singapore.

## **Asia, Central**

Armenia, Azerbaijan, Georgia, Kazakhstan, Kyrgyzstan, Mongolia, Tajikistan, Turkmenistan, Uzbekistan.

## **Asia, East**

China, Hong Kong, Democratic Peoples' Republic of Korea.

## **Asia, South**

Afghanistan, Bangladesh, Bhutan, India, Nepal, Pakistan.

## **Asia, Southeast**

Cambodia, Indonesia, Lao PDR, Malaysia, Maldives, Mauritius, Myanmar, Philippines, Seychelles, Sri Lanka, Thailand, Timor-Leste, Viet Nam.

## **Australasia**

Australia, New Zealand.

## **Caribbean**

Antigua and Barbuda, Bahamas, Barbados, Belize, Cuba, Dominica, Dominican Republic, Grenada, Guyana, Haiti, Jamaica, Saint Kitt's and Nevis, Saint Lucia, Saint Vincent and the Grenadines, Suriname, Trinidad and Tobago.

## **Europe, Central**

Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Czech Republic, Hungary, Macedonia, Montenegro, Poland, Romania, Serbia, Slovakia, Slovenia.

## **Europe, Eastern**

Belarus, Estonia, Latvia, Lithuania, Moldova, Russian Federation, Ukraine.

## **Europe, Western**

Andorra, Austria, Belgium, Cyprus, Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Israel, Italy, Liechtenstein, Luxembourg, Malta, Monaco, Netherlands, Norway, Portugal, San Marino, Spain, Sweden, Switzerland, United Kingdom.

## **Latin America, Andean**

Bolivia, Ecuador, Peru.

## **Latin America, Central**

Colombia, Costa Rica, El Salvador, Guatemala, Honduras, Mexico, Nicaragua, Panama, Venezuela.

## **Latin America, Southern**

Argentina, Chile, Uruguay.

## **Latin America, Tropical**

Brazil, Paraguay.

## **North Africa / Middle East**

Bahrain, Iran, Iraq, Jordan, Kuwait, Lebanon, Oman, Qatar, Saudi Arabia, Syrian Arab Republic, Turkey, United Arab Emirates, Yemen, Algeria, Egypt, Libyan Arab Jamahiriya, Morocco, Tunisia.

**North America, High Income**

Canada, United States.

**Oceania**

Cook Islands, Fiji, Kiribati, Marshall Islands, Micronesia, Nauru, Niue, Palau, Papua New Guinea, Samoa, Solomon Islands, Tonga, Tuvalu, Vanuatu.

**Sub-Saharan Africa, Central**

Angola, Central African Republic, Congo, DR Congo, Equatorial Guinea, Gabon.

**Sub-Saharan Africa, East**

Burundi, Comoros, Djibouti, Eritrea, Ethiopia, Kenya, Madagascar, Malawi, Mozambique, Rwanda, Somalia, Sudan, Tanzania, Uganda, Zambia.

**Sub-Saharan Africa, Southern**

Botswana, Lesotho, Namibia, South Africa, Swaziland, Zimbabwe.

**Sub-Saharan Africa, West**

Benin, Burkina Faso, Cameroon, Cape Verde, Chad, Côte d'Ivoire, Gambia, Ghana, Guinea, Guinea-Bissau, Liberia, Mali, Mauritania, Niger, Nigeria, Sao Tome and Principe, Senegal, Sierra Leone, Togo.

## Appendix 5: Age intervals presented in the Toolkit

0-4 years

5-9 years

10-14 years

15-19 years

20-24 years

25-29 years

30-34 years

35-39 years

40-44 years

45-49 years

50-54 years

55-59 years

60-64 years

65+ years