Tool for Assessing Health Needs

in relation to

Congenital Heart Disease

Part of the PHG Foundation Toolkit for Assessing Health Needs in relation to Congenital Disorders

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Needs Assessment Tool for Congenital Heart Disease

Country/Territory of interest for present needs assessment on Congenital Heart Disease:

CHD-0 INTRODUCTION

Welcome to the Needs Assessment Tool for Congenital Heart Disease (CHD). This Tool consists of seven sections, which are explained briefly in the Guide:

- the Country Profile
- the Epidemiology section
- the Interventions section
- the Needs Assessment section
- the Situation Assessment
- the Initial Prioritisation
- the Summary Report

The narrative and the written instructions are contained in the Tool, while numerical input and calculations are performed in the Calculator. The Tool and the Calculator should be used alongside one another. Where you need to put data into the Calculator, you will see an instruction.

Decision points

At certain points you will be prompted to decide whether it is necessary to continue with your present needs assessment. If the burden is low, for example, you may decide your efforts are better used on another topic, but this should be made explicit.

Subpopulations

If there is substantial variation in burden or service factors between population sub-groups, a whole-population needs assessment may not be appropriate. It may be necessary to conduct separate assessments for the individual groups, or to focus your assessment on a group that is particularly affected. At the minimum, you should ensure that substantially higher or lower rates in an identified population sub-group do not lead to inaccurate estimates for the whole population.

CHD-CP COUNTRY PROFILE

Demographic and health service factors are key determinants of the scale of congenital disorders and of the potential to provide care and prevention.

Note: If you or others coordinating PHG needs assessments have already completed Demography and Health services sheets in another topic Calculator for this population, you can copy that data into the present Calculator.

Population definition: Briefly describe the population if you are not using the whole country.

Some sources containing data relevant to the Country Profile are given in Appendix 1, located at the end of this document.

CHD-CP1 Demography

Demographic factors in a population have important effects on the burden of congenital disorders. Variables such as maternal age and level of consanguineous marriage affect the incidence of disorders, while variables such as birth rate and contraceptive prevalence affect the absolute number of births. Other indicators are useful for understanding the general context.

In the sheet of the Calculator named 'Demography' there are estimates of various important demographic indicators. You can add data from your own sources.

>>> Go to Calculator sheet Demography

CHD-CP2 Health services

Please give a summary description of the operation of health services and programmes in the country or territory. Describe their accessibility and coverage, and who is responsible for them.

Please list relevant national health policies, legislation and guidelines in relation to the pre-conception period, pregnancy and childhood, including genetic services and screening for genetic conditions.

There are several variables that it will be important to consider when assessing the potential for change and when completing the prioritisation process. Please now go to the Health Services sheet in the Calculator (HealthServices) and enter estimates of the health-service indicators listed there.

>>> Go to Calculator sheet HealthServices

Please summarise the country profile, highlighting where the indicators are unsatisfactory. Comment on areas for improvement in the indicators.

CHD-E EPIDEMIOLOGY

This section helps you to bring together epidemiological data related to Congenital Heart Disease, to understand the burden in your setting. The Calculator sheets already contain modelled estimates from the PHGDB; note that these estimates do not include CHD associated with chromosomal disorders (e.g. Down's syndrome) and other non-cardiac malformations. You may add data from research studies, surveillance systems or other sources, assessed for representativeness and quality.

Decision point: You may skip this section if you do not know of further estimates or just prefer to use the PHGDB estimates. If your population is not the total population of your country or territory, the PHGDB estimates may not be accurate.

CHD-E1 Country and comparative epidemiology

First, please complete some definitions as used in your country in Box CHD-E1.

Box CHD-E1: Definitions

Terms	Enter definition here
Live birth	
Still birth	
Miscarriage	

CHD-E1.1 Summary country epidemiology for Congenital Heart Disease

This section summarises the epidemiology of Congenital Heart Disease in your country. The aim is to record basic 'headline' data for the prevalence of Congenital Heart Disease in your country/territory, and the resulting mortality. Estimates from the PHGDB are contained in the CHD-E1.1 Calculator sheet.

Once you have completed the epidemiology section, you will be asked to consider whether you need to update this section.

>>> Go to Calculator sheet CHD-E1.1

CHD-E1.2 International comparative epidemiology

This section allows you to compare the situation in your population to the pre-populated estimates at national, regional and world level. If you are not using the PHGDB national estimates you will need to copy your chosen estimates from sheet CHD-E1.1 into the appropriate column here.

If you would prefer a different comparator, you can obtain PHGDB estimates for that country/territory from sheet CHD-E1.1 of the Calculator *for that country/territory*, which you can get from the Toolkit website.

>>> Go to Calculator sheet CHD-E1.2

Note: The following sections CHD-E2 and CHD-E3 ask for data from research studies, surveillance activities and other sources. Less detailed estimates of prevalence and effect are given by the PHGDB, in case such data are not available for your population.

CHD-E2 Data on affected pregnancies

In this section you will record data on live births and still births affected by Congenital Heart Disease, and terminations of pregnancy due to Congenital Heart Disease. If national or local estimates are not available, please move to section E2.4 which gives you estimates from PHGDB.

CHD-E2.1 Data on affected pregnancies: Research studies

Are national or local estimates for the prevalence of affected births available from research studies? If not, please move to section CHD-E2.2.

If research studies with information on birth prevalence of Congenital Heart Disease in your population are available, please list these here, including an indication of their quality and findings.

Table CHD-E2.1 Research studies on pregnancies affected by Congenital Heart Disease

Study author, year, site	Sample size	Study quality and representativeness	Main findings

Comment on existing studies and the quality of information they provide on the birth prevalence for your country and sub-groups of the population.

Now copy these studies into the Calculator sheet CHD-E2.1 and complete that sheet.

>>> Go to Calculator sheet CHD-2.1

CHD-E2.2 Data on affected pregnancies: Surveillance data

Are data on pregnancies affected by Congenital Heart Disease available from surveillance systems, for your population? If not, please move on to section CHD-E2.3. If surveillance data are available, please fill in the table in Calculator sheet CHD-E2.2.

>>> Go to Calculator sheet CHD-E2.2

CHD-E2.3 Data on affected pregnancies: Other sources

Are there other sources of data with information on affected live births, still births or terminations of pregnancy? Sources of such data might include hospitals, primary care, or surveys or estimates by charities with specific interest in the condition.

If yes, it is important to consider the completeness, quality and representativeness of the data. In Calculator sheet CHD-E2.3 you will enter basic numbers of affected live births, still births and terminations of pregnancy recorded from your data source. You will also estimate numbers for the whole country/territory, based on an assessment of how complete the source data is, and how much of the country/territory it covers. You will finally select the best estimates based on these data sources.

If the burden in the population covered by these data sources is different from the burden in the total population of your country/territory, you can weight your data. For a brief description of weighting, please see the Weighting section in the Guide.

>>> Go to Calculator sheet CHD-E2.3

If you do not have data from other sources, please continue to section CHD-E2.4.

CHD-E2.4 Summary of affected pregnancies

You may now combine estimates from research, surveillance and other health sector data and compare them to data from the PHGDB. Then you may choose your final estimates.

Please ensure you enter a chosen estimate in the appropriate column as these will be used later.

>>> Go to Calculator sheet CHD-E2.4

CHD-E2.5 Sub-population variation in affected pregnancies

If the birth prevalence rates vary by population sub-group (e.g. geographically or according to another factor), please 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.

>>> Go to Calculator sheet CHD-E2.5

CHD-E3 Mortality data

Completing this section will help to show what the burden of mortality from Congenital Heart Disease is in your population. If national or local estimates are not available, please move to section E3.4 which gives you estimates from PHGDB.

CHD-E3.1 Mortality data: Research studies

Are national or local condition-specific mortality estimates available from research studies? If not, please continue to section CHD-E3.2. If study estimates are available, please complete the table below on studies (including unpublished) providing mortality information in the

country. Be aware of the need to differentiate between age groups when considering mortality – the Calculator sheet asks for mortality estimates for different age groups.

Table CHD-E3.1 Research studies on mortality due to Congenital Heart Disease

Source, year, site	Sample size	Age groups covered	Study quality and representativeness	Main findings

Comment on existing studies and on the quality of information they provide on mortality in the country and population sub-groups.

Now, copy the table of studies into Calculator sheet CHD-E3.1 and enter the best estimates for condition-specific mortality by age-group (infant, under-5, etc).

>>> Go to Calculator sheet CHD-E3.1

CHD-E3.2 Mortality data: Vital registration data

If there are national or local vital registration mortality statistics with information on Congenital Heart Disease, you can use sheet CHD-E3.2 of the Calculator to record numbers and rates of affected deaths. If there are no vital registration statistics, please continue to section CHD-E3.3.

It is important to consider sub-registration of deaths and under-ascertainment of specific causes of death. The tables in Calculator sheet CHD-E3.2 allow you first to enter registered deaths for various age groups, and second to estimate numbers and ratios of deaths for the whole country/territory, based on an assessment of how complete the vital registration data is, and how much of the country/territory it covers.

If the burden in the population covered by your vital registration data is different from the burden in the total population of your country/territory, you can weight your data. For a brief description of weighting, please see the Weighting section in the Guide.

>>> Go to Calculator sheet CHD-E3.2

CHD-E3.3 Mortality data: Other sources

If other sources have information on mortality due to the condition, please enter those sources into this table.

Table CHD-E3.3 Other sources of data on mortality due to Congenital Heart Disease

Source, year, site	Sample size	Age groups covered	Study quality and representativeness	Main findings

Now copy these sources into the Calculator sheet CHD-E3.3 and complete the quantitative estimates in that sheet.

>>> Go to Calculator sheet CHD-E3.3

CHD-E3.4 Summary mortality estimates

Now, please combine estimates from research, surveillance and other health sector data and compare them to data from the PHGDB. Then choose the best estimates.

Please ensure you enter a chosen estimate, in the appropriate column as these will be used in later.

>>> Go to Calculator sheet CHD-E3.4

CHD-E3.5 Sub-population variation in mortality

Does condition-specific mortality vary between identifiable sub-groups in your population (e.g. geographically or according to other factors)? If not, continue to section CHD-E4.

If the mortality does vary by population sub-group, indicate any population sub-groups with different mortality estimates from the whole population and describe reasons for variation.

>>> Go to Calculator sheet CHD-E3.5

CHD-E4 Population prevalence

This section should make clear what the prevalence of Congenital Heart Disease is in your population. Are national or local estimates available for the population prevalence of affected persons? If not, please move to section CHD-E4.3.

CHD-E4.1 Population prevalence: Research studies

Are there research studies (including unpublished) providing prevalence estimates of Neural Tube Defects in your population? If so, please enter them in table CHD-E4.1. If not, please move to section CHD-E4.2.

Table CHD-E4.1 Research studies on population prevalence of Congenital Heart Disease

Source, year, site	Sample size	Study quality and representativeness	Main findings and comments

Comment on these studies and on the quality of information they provide on the population prevalence for the country or for sub-groups of the population.

Use the studies above to generate an estimate of the general population prevalence. Move to Calculator sheet CHD-E4.1 and enter the best estimates for the overall prevalence of Congenital Heart Disease in your population. Give a range of values to reflect uncertainty of estimates and within-country variation. If studies are not representative of the whole country population you may wish to adjust the results.

>>> Go to Calculator sheet CHD-E4.1

CHD-E4.2 Population prevalence: Other sources

Are there other sources of data with information on the population prevalence of Congenital Heart Disease in your country/territory? Sources of such data might include hospitals, primary care, or surveys or estimates by charities with specific interest in the condition. If so, please complete this table. If not, please move to section CHD-E4.3.

Table CHD-E4.2 Other sources of data on population prevalence of Congenital Heart Disease

Source, year, site	Sample size	Study quality and representativeness	Main findings

Comment on existing data from health services and other sources, including quality of information they provide on the population prevalence for the country and sub-groups of the populations.

Use data from the sources above to generate an estimate of the general population prevalence. Move to Calculator sheet CHD-E4.2 and enter the best estimates for the overall prevalence of Congenital Heart Disease in your population. Give a range of values to reflect uncertainty of estimates and within-country variation.

>>> Go to Calculator sheet CHD-E4.2

CHD-E4.3 Population prevalence summary

Now, please combine estimates from research and other sources and compare them to data from the PHGDB. Then choose the best estimates.

Please ensure you enter a chosen estimate, in the appropriate column as these will be used in later.

>>> Go to Calculator sheet CHD-E4.3

CHD-E4.4 Sub-population prevalence variation

Does the population prevalence vary across the country/territory?

If the prevalence varies by population sub-group (e.g. geographically or according to other factors), indicate any population sub-groups with different prevalence estimates from the whole population and describe reasons for variation.

First, describe reasons for choice of population sub-groups.

Now, go to the Calculator and enter data on prevalence variation by population sub-group.

>>> Go to Calculator sheet CHD-E4.4

CHD-E4.5 Population prevalence: Data needs

Please list below any needs for further data from research, and outline whether and how these data could be obtained.

Please list below any needs for further surveillance and health services data (or improvement in data quality) and outline how these data could be obtained.

Note: You may now want to revisit the national and comparative epidemiology profiles completed previously (in sheets CHD-E1.1 and 1.2 of the Calculator).

CHD-INTERV FOLIC ACID EFFECTS AND PRENATAL DIAGNOSIS

CHD-Interv1 Folic acid effects: Fortification

Fortification of common foodstuffs with folic acid can raise the folate levels of the entire population. In the related Calculator sheet you can:

- estimate the effect of fortification in your population, and
- discover the potential effect of hypothetical fortification regimes.

>>> Go to Calculator sheet CHD-Interv1

CHD-Interv2 Folic acid effects: Supplementation

In addition to the population effect of fortification with folic acid, specific supplementation of folic acid (in the form of folic acid pills) can be given to pregnant women to encourage necessary folate levels for correct neural tube formation. This supplementation has an effect on its own.

When fortification is already in place in the population, the extra effect of supplementation is less than the freestanding effect of supplementation: In this Toolkit, the effect of supplementation in the presence of fortification is assumed to be 10% of the effect of supplementation alone. This assumption can be varied in Calculator sheet CHD-Interv2.

In the related Calculator sheet you can:

- estimate the effect of folic acid supplementation alone, and
- estimate the effect of supplementation in the presence of fortification.

>>> Go to Calculator sheet CHD-Interv2

CHD-Interv3 Effects of prenatal screening and pregnancy management

Prenatal screening can identify defects in the fetal heart, and appropriate management of the pregnancy can influence morbidity and mortality. Calculator sheet CHD-Interv3 allows you to estimate the potential effect of PNS and pregnancy management.

>>> Go to Calculator sheet CHD-Interv3

CHD-NA NEEDS ASSESSMENT SECTION

CHD-NA1 Epidemiology

CHD-NA1.1 The size of the problem

In the epidemiology section above, you chose estimates for the burden of Congenital Heart Disease and for mortality indicators. The Calculator sheet CHD-NA1 contains tables recording the chosen estimates from the Calculator sheets CHD-E2.4 and CHD-E3.4. You may create similar tables for specific sub-groups of the condition as appropriate.

>>> Go to Calculator sheet CHD-NA1

CHD-NA1.2 Preliminary assessment of public health significance

Based on the epidemiology and your experience, how do you rate this as a public health problem in the country or territory in relation to all causes of congenital disorders?

Very low	Low	Medium	High	Very high	Do not know

Explain your choice.

Decision point: If you do not consider this to be a significant public health problem and no specific policies and interventions are required as a priority, you may stop here and move to another topic. Otherwise, continue with section CHD-NA2.

CHD-NA2 Assessment of epidemiology, policies, services and information

CHD-NA2.1 Desired situation

First outline the desired situation ('where do we want to be?') in relation to the epidemiology, care and prevention of the condition in the following areas.

Epidemiology (outcomes indicators, e.g. for prevalence and mortality)

Policies and programmes that would be optimal for delivering effective care and prevention in your country or region

Services and interventions that may be delivered, such as prenatal screening, diagnosis, counselling and interventions aimed at risk factors

Information availability (e.g. registries, vital statistics, health service indicators)

Desired outputs resulting from action (e.g. availability, coverage and quality of policies, interventions and services)

CHD-NA2.2 Current situation and gaps

Now please assess the current situation and unmet needs ('where are we now?'), indicating potential areas for action.

CHD-NA2.2.1 Policy and programmes

Briefly list any policies or programmes for the care and prevention of Congenital Heart Disease in your country or territory, and who is responsible for them (e.g. Institution, Ministry or Department).

Care

Prevention

Are there gaps or inadequacies in policies or programmes and in their implementation? Give details.

If yes, are there plans to address them? Give details.

What can be done to tackle unmet needs?

CHD-NA2.2.2 Services and interventions

List services and interventions for prevention and care, and comment on their quality and who provides them.

Prevention before pregnancy, both directed to high risk groups and population wide (e.g. multivitamin and folic acid supplementation and rubella vaccination programmes)

Prevention during pregnancy (e.g. prenatal screening)

Care and prevention after birth (e.g. newborn screening, medication, catheterisation, surgery, rehabilitation)

Are the above services and interventions well integrated with other health services (e.g. maternal and child health services)?

How do these target people at different life stages (i.e. before and during pregnancy and after birth)?

Are there appropriate and integrated pathways for prevention and care (e.g. communications between health service staff, and referral mechanisms)?

How are services and interventions monitored and evaluated?

Are services and interventions satisfactorily delivered?

Are services and interventions delivered across the country or territory equitably, according to the needs of different populations?

Are there any gaps or inadequacies in the delivery of services and interventions? If yes, what are the main reasons (e.g. lack of priority, planning, financial resources, facilities and equipment, trained personnel, managerial deficiencies)?

If there are gaps, are there plans to address them? Give details.

If not, is there a need for service changes or implementation of new services or interventions? List what could be done and how.

CHD-NA2.2.3 Information needs

Comment on the quality of any existing surveillance and research data that are relevant to the condition.

Is there a need for changes in surveillance systems for the condition?

If there are unmet information needs, how much does the absence of appropriate **surveillance data** impede action?

What can be done?

Is there a need for new research in relation to the condition?

If there are unmet information needs, how much does the absence of appropriate **research data** impede action?

What can be done?

Summary of the main gaps or unmet needs

Use Table CHD-NA2 to enter the level of met **needs** for policies and programmes, services and interventions, considering key life stages as appropriate. Use a numerical code system from 1 to 5, to reflect (1) mostly unmet (high need) to (5) mostly met (low need), with '3' representing an intermediate level of met needs. Therefore '1' represents an unsatisfactory situation, and '5' represents an optimum situation. You may use the action areas listed below, and add items as you find appropriate.

Table CHD-NA2 Summary of levels of health needs in relation to Congenital Heart Disease

Action areas	**Policies/ Programmes**	**Services and Interventions**			**Overall**
		Before Pregnancy	**During Pregnancy**	**After Birth**	
Public education including counselling about risk factors*					
Multivitamin and folic acid supplementation				n/a	
Management of diseases e.g. diabetes, PKU				n/a	
Rubella vaccination			n/a	n/a	
Susceptibility screening				n/a	
Prenatal diagnosis		n/a		n/a	
Termination of pregnancy		n/a		n/a	
Newborn screening		n/a	n/a		
Newborn diagnosis		n/a	n/a		
Primary care diagnosis		n/a			
Surgical care		n/a	n/a		
Paediatric cardiology		n/a	n/a		
Paediatric cardiac surgery		n/a	n/a		
Acute clinical care					
Long term clinical care					
Social care					
Disability support		n/a			
Support group involvement					
Surveillance					
Research					
Professional education					
Workforce training					

* Examples include obesity, use of alcohol, medications, solvents, family history, previous affected births.

Use the space below to summarise the main gaps or unmet needs identified.

CHD-NA3 Assessment of intervention options

In this section you will consider what effect different interventions can have on the burden of Congenital Heart Disease in your population.

CHD-NA3.1 Quantitative assessment of interventions

Here, you should fill in data relating to the prevalence of Congenital Heart Disease in different intervention scenarios: In the absence of interventions, in the current situation, and in the desired situation.

Table CHD-NA3a in Calculator sheet CHD-NA3 relates to 'potential cases' – expected numbers of cases and rates in the absence of any interventions (if coverage = zero).

Please note: there is no Calculator sheet NA2. This is deliberate!

>>> Go to Calculator sheet CHD-NA3

Tables CHD-NA3b to NA3e in Calculator sheet CHD-NA3 refer to the current and target (desirable) situations for interventions before birth and after birth. Please enter data in these tables. You may add or delete rows as appropriate.

>>> Return to Calculator sheet CHD-NA3

Table CHD-NA3f in Calculator sheet CHD-NA3 refers to outcomes. Figures for 'current situation' come from Tables CHD-NA1a and NA1b.

>>> Return to Calculator sheet CHD-NA3

CHD-NA3.2 Qualitative assessment of interventions

Now consider existing interventions and their coverage, effectiveness, cost-effectiveness, and current impact. Use numbers between '1' (very low) and '5' (very high) to complete Table CHD-NA3.2a. Please enter or delete rows as appropriate.

Table CHD-NA3.2a **Qualitative** assessment of the impact of **current** interventions

Interventions	Coverage	Effectiveness	Cost-effectiveness	Impact
Before pregnancy				
Family planning, education				
Multivitamin and folic acid supplementation				
Rubella vaccination				
During pregnancy				
Prenatal diagnosis				
Multivitamin and folic acid supplementation				
Control of teratogens				
Termination of pregnancy				
After birth				
Newborn screening				
Newborn diagnosis				
Echocardiology services				
Primary care diagnosis				
Paediatric cardiology				
Paediatric cardiac surgery				
Acute clinical care				
Social care and support				
Rehabilitation				

Now consider the potential for the implementation of new interventions or changes to existing ones, in relation to their achievable coverage, effectiveness, cost-effectiveness and potential impact. Use numbers between '1' (very low) and '5' (very high) to complete Table CHD-NA3.2b. Please enter or delete rows as appropriate.

Table CHD-NA3.2b Qualitative assessment of the **expected impact** of interventions

Interventions	Achievable coverage	Effectiveness	Cost-effectiveness	Impact
Before pregnancy				
Family planning, education				
Multivitamin and folic acid supplementation				
Rubella vaccination				
During pregnancy				
Prenatal diagnosis				
Multivitamin and folic acid supplementation				
Control of teratogens				
Termination of pregnancy				
After birth				
Newborn screening				
Newborn diagnosis				
Echocardiology services				
Primary care diagnosis				
Paediatric cardiology				
Paediatric cardiac surgery				
Acute clinical care				
Social care and support				
Rehabilitation				

CHD-NA4 Situation assessment

Now consider your environment and describe the **S**trengths, **W**eaknesses, **O**pportunities and **T**hreats in relation to policies and services, using the SWOT diagram in Table CHD-NA4.

Table CHD-NA4 SWOT diagram

Internal environment	**External environment**	
Strengths	**Opportunities**	**+**
Weakness	**Threats**	–

CHD-NA5 Initial prioritisation: Comparing interventions

The prioritisation team and processes

List the people and organisations invited to and involved in the initial prioritisation process in Table CHD-NA5a, and briefly explain how they were chosen.

Table CHD-NA5a The prioritisation team

Person invited	Organisation represented	Accepted (Y/N)

Brief explanation of choice of participants and give any other comments

Now consider in the group your ground rules, prioritisation criteria and action areas and complete Tables CHD-NA5b to CHD-NA5d. Start with the ground rules.

Table CHD-NA5b Ground rules for the prioritisation process (add rows if needed)

Now list in Table CHD-NA5c the prioritisation criteria you will use. You may wish to add weights to each criterion (from '0' to '1') in the table.

Table CHD-NA5c List of criteria for prioritisation of interventions (add rows if needed)

Based on your assessment of needs, please consider and list in Table CHD-NA5d action areas for consideration.

Table CHD-NA5d List of action areas for consideration (add rows if needed)

Based on the criteria selected, compare the action areas and rank them from the highest to the lowest priority. You may enter the results directly, following your discussions. You may find it helpful to use decision analysis software, so as to do it in a more systematic way (see the Prioritisation document). Show your results in Table CHD-NA5e, by entering the selected 'Action Areas' from the highest priority (1) onwards, using as many rows as appropriate. Tick the last column for all action areas that you consider are of sufficient priority to carry over to the later stages of the prioritisation process. This will enable these results to be compared with those for other conditions or topics at a later stage.

Table CHD-NA5e List of priority action areas and interventions for Congenital Heart Disease

Priority	Action area	Carry over
1. highest		
2.		
3.		
4		
5		

You have completed this Section! Now please proceed to the Summary Report.

CHD-NA6 Summary report

It is now time to bring together the main findings of your needs assessment into a summary report. This will present in one place the basic information about the burden of Congenital Heart Disease, the present state of interventions and the potential to improve care and reduce incidence.

Briefly describe the population and condition.

Briefly describe the epidemiology of the condition, including within-country and international comparisons, and highlighting any high risk groups[1].

List the main services and interventions currently available for the care and prevention of the condition[2].

[1] Possible reference sections: E1.1, NA1.1

[2] You may wish to include an assessment of the effectiveness, cost-effectiveness, coverage, quality and level of satisfaction with the interventions or services. Possible reference sections: NA3.1, NA3.2

Are there any threats to the continuation of services?[3]

What are the unmet needs as assessed by the Toolkit?[4]

Is it feasible to meet the identified needs?[5]

[3] For example, in relation to resources, acceptability, and competing priorities. Possible reference section: NA2.2.2

[4] You may wish to consider the following questions: i) What are the main needs? ii) Is appropriate information available? iii) Are appropriate legislation, policies and programmes in place? iv) Are appropriate services and interventions in place? v) Are prevalence rates (both at birth and population level) as low as they can be? vi) Is prevention before pregnancy being delivered effectively, cost-effectively and according to need? vii) Is prevention during pregnancy being delivered effectively, cost-effectively and according to need? viii) Is prevention and care after birth being delivered effectively, cost-effectively and according to need? ix) Are prevention and care activities being delivered fairly (equitably)? Possible reference sections: NA2 and NA3

[5] You may wish to consider strengths, weaknesses, opportunities and threats. Possible reference section: NA4

What actions may be required to respond to the unmet needs?

Describe how the prioritisation has been done and the main findings.

List the planned activities and how they will be evaluated[6].

[6] Possible reference section: NA5e

List the proposed next steps.

APPENDIX 1 – SOURCES OF DATA FOR THE COUNTRY PROFILE

For demographic, socio-economic and other indicators for your country or world regions, you may use the links below or other sources available to you.

1. Consanguinity
http://www.consang.net/index.php/Global_prevalence_tables

2. Countdown to 2015 (profiles for selected countries)
http://www.childinfo.org/countdown_638.htm

3. Global health Observatory (GHO)
http://www.who.int/gho/en/index.html

4. Health Indicators database. Pan American Health Org (PAHO)
http://ais.paho.org/phip/viz/basicindicatorbrowaser.asp

5. Health of Nations
http://www.healthofnations.com/countries/map/outcomes/life

6. Immunisation
http://apps.who.int/immunization_monitoring/en/globalsummary/countryprofileresult.cfm

7. Indicator definitions. (WHO)
http://www.who.int/whosis/indicators/en

8. UN Demographic Yearbook (UNDY) series
http://unstats.un.org/unsd/demographic/products/dyb/dyb2.htm

9. UN Statistics Division
http://unstats.un.org/unsd/demographic/products/socind/health.htm

10. UNICEF country statistics
http://www.unicef.org/statistics/index_countrystats.html

11. UNICEF reports on The State of the World's Children
http://www.unicef.org/sowc08/statistics/statistics.php

12. WHO data and statistics (various links)
http://www.who.int/research/en/

13. WHO Statistical Information System (WHOSIS)

http://www.who.int/whosis/whostat/2010/en/index.html

Please list your own sources of data below

1.

2.

3.