Tool for Assessing Health Needs

in relation to

Health Services

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

Version,1.1 September 2013

PHG Foundation Needs Assessment Tool for Health Services

Country / Territory of interest for present needs assessment on Health Services

HSER-0   INTRODUCTION

Welcome to the PHG Foundation Congenital Disorders Needs Assessment Tool, for Health Services (HSER). This Tool consists of five sections, which are explained briefly in the Guide:

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

The narrative and the written instructions are contained in this 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 variation between population sub-groups is substantial, 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.

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HSER-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 conducting 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.

HSER-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

HSER-CP2 Health services

Ideally, activities related to the care and prevention of congenital disorders are well integrated into health services, and particularly into family planning, women's, maternal, newborn, child, genetic and public 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 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 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.

HSER-NA NEEDS ASSESSMENT SECTION

HSER-NA1 Preliminary assessment of public health need

This section will enable you to quickly access the main risk factors and conditions that you wish to address. The focus is on the operation of health and other (public) services in general and how well they are prepared to deal with the care and prevention of congenital disorders before, during and after pregnancy. In addition you may wish to list priority areas for action in relation to risk factors, specific conditions, policies, programmes and services.

Calculators HSER-NA1, and Tables HSER-NA1.2a and 1.2b should help you to make an initial assessment of the level of need for the health services in your country or region.

Calculator HSER-NA1 lists some of the more common groups of congenital disorders. Please insert data for your country or region, where available. Please indicate if the conditions are unlikely to be of significance in your population (NS) or if no data are available (ND) even if it may be significant.

Tables HSER-NA1.2a and 1.2b ask you to estimate the level of met needs (1 to 5) to reflect (1) mostly unmet need (high need) to (5) mostly met (low need), with '3' representing intermediate levels of met needs, Therefore '1' represents an unsatisfactory situation, and '5' represents an optimum situation. Please add rows as appropriate.

Table HSER-NA1.2a   Public health significance and level of unmet need

Conditions	Public health significance*	Level of unmet need
Autosomal chromosomal disorders		
Sex chromosomal disorders		
Chromosomal disorders (all)		
Congenital heart disease		
Neural tube defects		
Orofacial clefts		
Other malformations		
Malformations (all)		
Sickle cell disease		
Thalassaemias		
Hb disorders (all)		
Other recessive SGD		
Dominant SGD		
X-linked SGD		
All SGD of clinical significance		
Rhesus haemolytic disease		
G6PD deficiency		
Environmental causes (all)		
Unknown causes		

SGD = single gene disorders
G6PD = glucose-6-phosphate dehydrogenase
* VL = very low; L = low; I = Intermediate; H= high; VH= very high

Table HSER-NA1.2b   Public health significance and level of unmet need

Groups of risk factors	Public health significance*	Level of unmet need
Consanguinity		
Infections in pregnancy		
Non-infectious diseases in pregnancy**		
Teratogens: exposure to e.g. alcohol, drugs		
Teratogens: Prescribed and over the counter drugs		
Environmental and occupational exposures		

* VL = very low; L = low; I = Intermediate; H= high; VH= very high
** diabetes, obesity, epilepsy

Use Table HSER-NA1.3 to estimate the prevalence of some risk factors: give percentages where these are available. If percentage estimates are not available, give a rough indication of the prevalence of risk factors using the column for qualitative assessment; enter values (1) mostly unmet need (high need) to (5) mostly met (low need), with '3' representing intermediate levels of met needs, Therefore '1' represents an unsatisfactory situation, and '5' represents an optimum situation. Please add rows as appropriate.

Table HSER-NA1.3   Estimated prevalence of some risk factors

Risk factor	Prevalence estimates (%)	Qualitative assessment	Source
In population			
Rubella vaccination coverage at 1 year of age			
Consanguineous unions			
Prevalence among women aged 15-44			
Rubella susceptibility			
Recreational drug consumption			
Alcohol consumption			
Tobacco consumption			
Unplanned pregnancies			
Pregnancies in women over 35 years of age (of total pregnancies in 15-44 year-olds)			
Syphilis			
Diabetes			
Epilepsy			

Now please list the main interventions for the care and prevention of congenital disorders that are relevant to your region.

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Use Table HSER-NA1.4 to estimate the coverage of relevant interventions. As above, please give percentages or an assessment of coverage from 1 to 5 (where 1 represents poor coverage and 5 represents very good coverage). Add further rows for other interventions you find relevant.

Table HSER-NA1.4   Estimated coverage of interventions

Intervention	Coverage estimates (%)	Qualitative assessment	Source
Preconception			
Family planning			
Preconception consultation			
Folic acid fortification of foods			
Salt iodisation			
Folic acid supplementation			
Screening for infectious diseases			
Advice on consanguinity			
Carrier testing in at-risk families			
Population carrier screening			
Pre-implantation genetic diagnosis			
Prenatal			
Prenatal screening for infection			
Prenatal screening for Rhesus			
Prenatal screening for diabetes			
Prenatal screening for Down's			
Prenatal screening for malformations			
Prenatal screening for inherited conditions			
Counselling for prenatal screening programmes			
Newborn			
Newborn screening			
Newborn diagnosis			
Referral for specific treatment			
Rehabilitation services			
Consultation and counselling for congenital disorders			
Presymptomatic testing for late-onset genetic disorders*			
Adolescence and adulthood			
Ongoing care and social support			
Recall of affected individuals for further genetics advice/testing at appropriate life stages			
Counselling/testing for at-risk family members			

*Only if the child would benefit from early initiation of effective prophylactic treatment.

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List services available for the care and prevention of congenital disorders, and include a brief evaluation of their operation and efficiency.

What are the perceived needs in relation to services for the care and prevention of congenital disorders? Which are the main parties/stakeholders expressing these needs?

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

Based on the information in the above tables and your experience, how do you rate the need to improve health services and other social services in order to deal effectively with the care and prevention of congenital disorders before, during and after pregnancy?

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 HSER-NA2.

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9

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HSER-NA2 Assessment of policies, services and information

HSER-NA2.1 Desired situation

First outline the desired situation ('where do we want to be?') in relation to health services in your country or territory, particularly in relation to congenital disorders. Where relevant take into account services operating in the preconception, prenatal, newborn and childhood periods separately.

Now consider what policies and programmes would be optimal for delivering effective health services for congenital disorders. Options include an integrated programme that provides advice, screening, diagnosis, care, support and prevention for a range of risks and conditions. Alternatively programmes may focus on particular conditions.

Policies and programmes

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Now consider services and interventions that maybe delivered by a health service for congenital disorders.

Services and interventions

Please comment on the availability of information (e.g. registries, epidemiological information, health service indicators).

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

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HSER-NA2.2 Current situation and gaps

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

HSER-NA2.2.1 Policy and programmes

Briefly list any key policies or programmes affecting the need for, access to or availability of health services related to the care and prevention of congenital disorders in your country or territory, and who is responsible for them (e.g. Institution, Ministry or Department). Consider policies and programmes affecting the problem at different points in time (e.g. the preconception, prenatal and newborn periods; care for disabled people; population-wide public health measures).

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

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

What else can be done to tackle unmet needs?

HSER-NA2.2.2   Services and interventions

Use Table HSER-NA2 to assess several aspects of relevant services that may influence the care or prevention of congenital disorders (please add rows if appropriate). For each area, consider the level of access; available resources (facilities, equipment, staff); service quality, service efficiency (in improving processes and outcomes) and equity. Entering values from (1) mostly unmet need (high need) to (5) mostly met (low need), with '3' representing intermediate levels of met needs. Please add rows as appropriate.

Table HSER-NA2   Assessment of health services for congenital disorders and unmet needs

Service area	Access	Resources	Quality*	Efficiency	Equity
Public health services					
Private health services					
Family planning and preconception services					
Prenatal care, screening and services					
Newborn screening and care					
Clinical genetic services					
Community genetics or outreach consultation (e.g. by midwives or community doctors)					
Laboratory services					
Genetic counselling					
Paediatric surgery					
Treatment services (non-surgical)					
Multidisciplinary clinics					
Neuro-development services					
Social services					
Rehabilitation services					

* Including adherence to high ethical standards (e.g. for informed consent, confidentiality, data protection and non-directive counselling.)

Make an explicit note of any major problems.

List the key services for care and prevention of congenital disorders and comment on their quality (including ethical standards) and who provides them.

Prevention before pregnancy, directed to high risk groups and population-wide (e.g. education on risks associated with advanced maternal age, carrier screening, advice on consanguinity, advice on smoking and alcohol)

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Diagnosis, advice and prevention during pregnancy (e.g. prenatal screening and diagnosis)

Care and prevention after birth (e.g. diagnosis, treatment, social support)

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

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15

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

Are there appropriate and integrated pathways for care and prevention?

How are services monitored and evaluated?

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16

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Are services being satisfactorily delivered (including maintenance of high ethical standards)?

Are services being delivered across the country or region according to the needs of different populations (equity)?

Are there any gaps or inadequacies in the delivery of services?

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

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

HSER-NA2.2.3 Information needs

Comment on the quality of any existing relevant surveillance data for congenital disorders, and other data covering effectiveness of health services for congenital disorders and the epidemiology of priority congenital disorders.

Is there a need for implementation or changes in information systems in relation to congenital disorders?

If there are unmet information needs, how far does the absence of appropriate data hamper action?
What can be done?

Is there a need for new research into health services related to congenital disorders? What can be done?

If there are unmet research needs, how far does the absence of appropriate research data hamper action?
What can be done?

Summary of the main gaps or unmet needs
(Please refer to Table NA1 in the Calculator and Tables NA1.2 and NA2 above.)

HSER-NA3   Qualitative assessment of services

Use Table HSER-NA3 to enter the level of met needs for policies and programmes, services and interventions. Consider the range of action areas and different life stages as appropriate. Use numbers from 1 to 5, to reflect (1) mostly unmet (high need) to (5) mostly met (low need). Therefore '1' represents an unsatisfactory situation and '5' an optimum situation. You may use the action areas listed below, and add or remove items as you find appropriate.

Table HSER-NA3   Qualitative assessment of the impact of **current** services

Action areas	Policies / Programmes	Services and Interventions			Overall
		Before Pregnancy	During Pregnancy	After Birth	
Public education*					
Control of risk behaviours around pregnancy**				n/a	
Control of environmental occupational exposures				n/a	
Rubella vaccination			n/a	n/a	
Nutrition: folic acid and iodine				n/a	
Preconception consultation/care			n/a	n/a	
Advice on consanguinity					
Preconception screening			n/a	n/a	
Family planning			n/a	n/a	
Prenatal screening		n/a		n/a	
Prenatal diagnosis		n/a		n/a	
Pregnancy termination		n/a		n/a	
Newborn screening		n/a	n/a		
Newborn diagnosis		n/a	n/a		
Childhood diagnosis					
Adolescence and adult diagnosis					
Primary care diagnosis		n/a	n/a		
Cascade screening		n/a	n/a		
High risk population newborn screening		n/a	n/a		
Community outreach					
Genetic clinical services					
Genetic lab services					
Surgical care		n/a	n/a		
Clinical care acute					
Clinical care chronic					
Social care					
Care of disabled					
Surveillance					
Research					
Professional education					
Workforce training					
Recognition of genetics as a specialty		n/a	n/a	n/a	
Research		n/a	n/a	n/a	
Professional education		n/a	n/a	n/a	
Workforce training		n/a	n/a	n/a	

* E.g. genetics literacy and education on risks of congenital disorders
**e.g. alcohol, tobacco, illicit drugs, over the counter and self-medication

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What are the main needs and gaps in health services related to congenital disorders? Assess legislation, policies, programmes, services, interventions and information, as well as effectiveness and cost-effectiveness.

Is it feasible to address these needs and gaps? What are the options?

HSER-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 HSER-NA4.

Table HSER-NA4   SWOT diagram

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

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HSER-NA5   Initial prioritisation: Comparing interventions

The prioritisation team and processes

List the persons and organisations invited for and involved in the initial prioritisation process in Table HSER-NA5a, and briefly explain how they were chosen.

Table HSER-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 HSER-NA5b to HSER-NA5d. Start with the ground rules.

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

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

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

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

Table HSER-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. If helpful, this can be done in a more systematic way using a decision analysis software (see the Prioritisation and Supporting document). Show your results in Table HSER-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 enough priority to carrying over to the latter stages of the prioritisation process. This will enable the comparison of these results with those for other conditions or topics at a later stage.

Table HSER-NA5e   List of priority action areas and interventions for health services

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

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

HSER-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 need for Health Services, the present state of interventions and the potential to improve care and reduce incidence.

Briefly describe the population and topic covered by this health needs assessment.

Briefly describe how the relevant services are organised[1].

List the main service activities and interventions currently available for the care and prevention of the congenital disorders[2].

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[1] Possible reference section: CP2

[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 include NA1-NA1.4

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

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

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

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[3] For example, in relation to resources, acceptability, competing priorities

[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 the main risk factors being addressed? vi) If appropriate, are prevalence rates, e.g. at birth and population level, as low as they can be?
vii) Is prevention and care being delivered effectively, cost-effectively and according to need?
viii) Are prevention and care activities being delivered fairly (equity)?
Possible reference section: NA3

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

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

Describe how the prioritisation has been done and the main findings[6].

List the planned activities and how they will be evaluated.

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[6] Possible reference section: NA5

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List the proposed next steps.

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

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

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

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

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.

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