



Tool for Assessing Health Needs

in relation to

Preconception Care and Screening

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

Version, 1.1 September 2013

PHG Foundation is a charity registered in the UK.

Company Number: 5823194 Charity Number: 1118664
Address: 2 Worts Causeway Cambridge CB1 8RN (UK)

PHG Foundation Needs Assessment Tool for Preconception Care and Screening

Country/Territory of interest for present needs assessment on Preconception Care and Screening

PCCS-0 INTRODUCTION

Welcome to the PHG Foundation Congenital Disorders Needs Assessment Tool, for Preconception Care and Screening (PCCS). 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 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.

PCCS-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.

PCCS-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](#)

PCCS-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 (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.

PCCS-NA NEEDS ASSESSMENT SECTION

PCCS-NA1 Preliminary assessment of public health need

This section should help you to make an initial assessment of the level of need for PCCS in your country or territory. You should complete the Tables using epidemiological data where available. If data are not available, please enter a qualitative assessment using a rating system of 1-5, where 1 indicates that the risk factor is not significant in your population, and 5 indicates a highly significant risk factor.

Calculator PCCS-NA1.1 deals with maternal and environmental risk factors for congenital disorders. Please enter estimates, including an indication of variation within your population.

>>> Go to Calculator sheet PCCS-NA1.1

Calculator PCCS-NA1.2 addresses genetic conditions whose birth prevalence may be influenced by preconception interventions such as carrier screening, preconception advice on increased risk due to family history or belonging to a high-risk population.

>>> Go to Calculator sheet PCCS-NA1.2

Based on this preliminary assessment and your experience, how do you rate the need for effective PCCS services as a public health issue in the country or region?

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 PCCS-NA2.

PCCS-NA2 Assessment of policies, services and information

PCCS-NA2.1 Desired situation

First outline the desired situation ('where do we want to be?') in relation to the prevalence of genetic and environmental risk factors in the preconception period.

Maternal risk factors and genetic congenital disorders

Now consider what policies and programmes would be optimal for delivering effective PCCS in your country or region. Options include an integrated programme providing advice, screening and support in the preconception period on the full range of risks and conditions that may affect a future pregnancy and infant. Alternatively (or in addition) policies or programmes may focus on the prevention of particular conditions such as neural tube defects or single gene disorders.

Policies and programmes

Now consider services that may be delivered in the preconception period, such as women's and reproductive health services; preventive services and interventions aimed at risk factors such as alcohol abuse, diabetes, epilepsy or teratogen exposure.

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)

PCCS-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.

PCCS-NA2.2.1 Policy and programmes

Briefly list any national policies or programmes for preconception care and preconception screening in your country or region, and who is responsible for them (e.g. Institution, Ministry or Department).

Preconception care

Preconception screening

Do you have an integrated preconception care programme? If yes, please describe.

Is preconception care delivered within other health care programmes (e.g. as part of family planning services) or as an isolated preconception care programme for a specific condition? Give details.

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

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

What else can be done to tackle unmet needs?

PCCS-NA2.2.2 Services and interventions

In Table PCCS-NA2, list and describe current preconception care and screening services. Describe any significant variations in the availability or delivery of services.

Table PCCS-NA2 Delivery of preconception interventions (add rows if needed)

Component	Tick if available*	Description	Variation**
Family planning services that include preconception care			
Advice on diet			
Advice on folic acid supplementation before conception			
Folic acid fortification			
Advice on avoidance of environmental & occupational teratogens			
Screening and treatment for syphilis			
Rubella immunisation and/or screening			
Screening for other infections (specify)			
Programmes and advice on smoking			
Programmes and advice on alcohol consumption			
Management of chronic conditions, including diabetes, obesity and epilepsy			
Advice on use of prescribed and over the counter medicine during pregnancy			
Discussion of relevant history for risk of congenital disorders, inherited disease or repeated miscarriage			
Carrier screening for genetic conditions e.g. haemoglobin disorders and G6PD deficiency			
Advice on risk of advanced age in pregnancy			

* Or enter n/a if not relevant for your population.

** Describe any significant variations in the programme coverage across the country/region and any sub-groups of the population who are under served by the programme.

Comment further on significant variations in programme coverage across the country/territory, and on any sub-groups of the population who are underserved by the programme.

How is the delivery of programmes monitored and evaluated?

Are the preconception services being satisfactorily delivered?

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

Are the policies, services and interventions well integrated with other initiatives (e.g. social, education, employment etc.)?

Are services 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 services or interventions? List what could be done and how.

PCCS-NA2.2.3 Information needs

Comment on the quality of any existent surveillance, other epidemiological and research data that is relevant to the conditions that you provide advice on or screen for before pregnancy (e.g. carrier screening) and also on data for programme monitoring.

Is there a need for implementation or changes in information systems in relation to preconception care or screening programmes?

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 in relation to preconception care or preconception screening? 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 Tables NA1.1 and NA1.2 in the Calculator and NA2 above.)

PCCS-NA3 Qualitative assessment of interventions

Now consider existing interventions and their coverage, effectiveness, cost-effectiveness, and their current impact (Table PCCS-NA3a) and expected impact (Table PCCS-NA3b). Use numbers from '1' (very low) to '5' (very high). Please add rows as appropriate.

Table PCCS-NA3a Qualitative assessment of the impact of **current** interventions

Intervention	Coverage	Effectiveness	Cost-effectiveness	Impact
Family planning services that include preconception care				
Advice on diet before conception				
Advice on folic acid supplementation before conception				
Folic acid fortification of foods				
Advice on avoidance of environmental and occupational teratogens				
Advice on risks of use of prescribed and other drugs				
Screening and treatment for syphilis before pregnancy				
Rubella immunisation and/or screening				
Screening for other infections that may be teratogenic				
Programmes and advice on smoking				
Programmes and advice on alcohol consumption				
Management of chronic conditions, including diabetes, obesity and epilepsy				
Discussion of relevant history for risk of congenital disorders, inherited disease or repeated miscarriage				
Carrier screening for genetic conditions e.g. haemoglobin disorders and G6PD deficiency				
Advice on risk of advanced age in pregnancy				

G6PD = glucose-6-phosphate dehydrogenase

Table PCCS-NA3b Qualitative assessment of the **expected** impact of changes and interventions

Intervention	Coverage	Effectiveness	Cost-effectiveness	Impact
Family planning services that include preconception care				
Advice on diet before conception				
Advice on folic acid supplementation before conception				
Folic acid fortification of foods				
Advice on avoidance of environmental & occupational teratogens				
Advice on risks of use of prescribed and other drugs				
Screening and treatment for syphilis before pregnancy				
Rubella immunisation and/or screening				
Screening for other infections that may be teratogenic				
Programmes and advice on smoking				
Programmes and advice on alcohol consumption				
Management of chronic conditions, including diabetes, obesity and epilepsy				
Discussion of relevant history for risk of congenital disorders, inherited disease or repeated miscarriage				
Carrier screening for genetic conditions e.g. haemoglobin disorders and G6PD deficiency				
Advice on risk of advanced age in pregnancy				

G6PD = glucose-6-phosphate dehydrogenase

PCCS-NA4 Quantitative assessment of interventions

The following sheets in the Calculator allow you to estimate the potential reduction in birth prevalence of various conditions, through preconception care and screening.

Note: If you or others conducting PHG needs assessments have already completed the intervention(s) sheets in another topic Calculator for this population, you can copy that data into the present Calculator.

- >>> Go to Calculator sheet PCCS-CHD
- >>> Go to Calculator sheet PCCS-DOWNS
- >>> Go to Calculator sheet PCCS-FASD
- >>> Go to Calculator sheet PCCS-NTD
- >>> Go to Calculator sheet PCCS-OFC
- >>> Go to Calculator sheet PCCS-RUB
- >>> Go to Calculator sheet PCCS-SYPH
- >>> Go to Calculator sheet PCCS-TER

PCCS-NA5 Situation assessment

Now consider your situation and describe the **Strengths**, **Weaknesses**, **Opportunities** and **Threats** in relation to policies and services, using the SWOT diagram in Table PCCS-NA5.

Table PCCS-NA5 SWOT diagram

Internal environment	External environment	
Strengths	Opportunities	+
Weakness	Threats	-

PCCS-NA6 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 PCCS-NA6a, and briefly explain how they were chosen.

Table PCCS-NA6a 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 PCCS-NA6b to PCCS-NA6d. Start with the ground rules.

Table PCCS-NA6b Ground rules for the prioritisation process (add rows if needed)

Now list in Table PCCS-NA6c the prioritisation criteria you will use. You may wish to add weights to each criterion (from '0' to '1') in the table.

Table PCCS-NA6c List of criteria for prioritisation of interventions (add rows if needed)

--

Based on your assessment of needs, please consider and list in Table PCCS-NA6d action areas for consideration.

Table PCCS-NA6d 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 PCCS-NA6e, 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 PCCS-NA6e List of priority action areas and interventions for preconception care and screening

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

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

PCCS-NA7 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 preconception care and screening 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 organised¹.

List the main service activities and interventions currently available for the care and prevention of the congenital disorders².

¹ Possible reference sections: 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 NA1.1, NA1.2, NA2.2.1.

Are there any threats to the continuation of services³?

What are the unmet needs as assessed by the Toolkit⁴?

Is it feasible to meet the identified needs⁵?

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

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

Describe how the prioritisation has been done and the main findings⁶.

List the planned activities and how they will be evaluated.

⁶ Possible reference section: NA6

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/hip/viz/basicindicatorbrowser.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.