

Tool for Assessing Health Needs

in relation to

Teratogens

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 Teratogens

Country/Territory of interest for present needs assessment on Teratogens:

TER-0 INTRODUCTION

Welcome to the PHG Foundation Congenital Disorders Needs Assessment Tool for Teratogens (TER). 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.

Please note this tool looks at teratogens broadly and encompasses all teratogen related congenital disorders. You may specify a particular teratogen if you wish to consider a narrow subset. In addition, if you would like to carry out a needs assessment with regards to specific teratogens, documents relating to alcohol, rubella, syphilis and nutritional deficiencies (folic acid and iodine) are listed under specific clinical topics.

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.



TER-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 ocated at the end of this document.
TER-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
TER-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.



	egislation and guidelines in relation to the pre- l, including genetic services and screening for
for change and when completing the priorit	ortant to consider when assessing the potential isation process. Please now go to the Health ices) and enter estimates of the health-service
>	>>> Go to Calculator sheet HealthServices
Please summarise the country profile, highli Comment on areas for improvement in the inc	ghting where the indicators are unsatisfactory.
,	



TER-NA NEEDS ASSESSMENT SECTION

TER-NA1 Preliminary assessment of public health need

This section should help you to make an initial assessment of the level of need for services and structures to mitigate risk from teratogens 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 TER-NA1.1 deals with a range of maternal and environmental teratogenic risk factors for congenital disorders. Please enter estimates, including an indication of variation within your population.

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

The Calculator sheet TER-NA1.2 contains tables which allow you to record epidemiological data with relation to teratogens if these are available. You may populate this table with data for teratogens broadly or you can create similar tables for specific sub-groups of teratogens as appropriate.

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

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

very low	LOW	Mealum	Hign	very nign	Do not know
Explain your ch	noice.				

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 TER-NA2.



TER-NA2 Assessment of policies, services and information

TER-NA2.1 Desired situation

First outline the desired situation ('where do we want to be?') in relation to the epidemiology, care and prevention with relation to congenital disorders caused by teratogens in the following areas:

Teratogenic risk factors and congenital disorders
Now consider what policies and programmes would be optimal for reducing congenitary disorders due to teratogens 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 reduction in exposure to particular teratogens.
Policies and Programmes



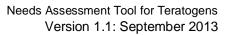
Now consider services that may be delivered such as women's and reproductive health services, preventive services, and interventions aimed at reducing teratogen exposure or providing information on teratogens.

nedications)	interventions (e.g			•		
	ent on the avail ngenital disorders				en informatio	on service:
Desired output Interventions a	ts resulting from nd services)	action (e.g.	availability,	coverage	and quality	of policies



TER-NA2.2 Current situation and gaps

Now please as potential areas	ssess the current situ for action.	ation and unmet	needs ('where are	e we now?'), indic	ating
	orders in your coun istry or Department).		and who is respo	onsible for them	(e.g.
Caro					
Prevention					





Are there gaps or inadequacies in policies or programmes and in their implementation? Gived details.
If yes, are there plans to address them? Give details.
What can be done to tackle unmet needs?



TER-NA2.2.2 Services and interventions

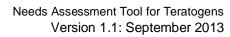
List services and interventions for prevention and care, and comment on their quality and who provides them.

In Table TER-NA2, list and describe current services aimed at reducing congenital disorders caused by teratogens. Describe any significant variations in the availability or delivery of services

Component	Tick if available*	Description	Variation**
Public education			
Professional education			
Legislation and regulation: Environmental			
Legislation and regulation: Occupational			
Legislation and regulation: Prescribed drugs			
Legislation and regulation: Non-prescribed drugs			
Workforce training			
Screening for teratogen exposure: environment			
Screening for teratogen exposure: workplace			
Information on teratogen effects and exposure risk			
Prenatal screening			
Prenatal diagnosis			
Termination of pregnancy			
Newborn screening			
Referral care plan			
Long term clinical care and related interventions			
Social care for those born with teratogen-induced			
congenital disorders.			
Disability support			
Education in schools			
Education in workplace			
Surveillance of exposures			
Surveillance of cases			
Research into teratogens * Or enter n/a if not relevant f			

^{*} 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 underserved by the programme.

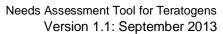




Comment further on significant variations in the coverage of services and interventions in the country/territory, and on any sub-groups of the population who are underserved.
Southly termony, and en any out groupe of the population who are analysed.
How is the delivery of these interventions monitored and evaluated?
Are the services being satisfactorily delivered?



services)?	
How do these target people at different life stages (i.e. before and during pregnancy after birth)?	/ and
Are there appropriate and integrated pathways for prevention and care? communications between health service staff, and referral mechanisms)	(e.g.





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 or legal regulation)?
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.



TER-NA2.2.3 Information needs

		quality of any congenital disc					eseard	ch data	on	exposure	to
		r implementa ted congenital			s in sı	urveilla	nce s	ystems	for	exposure	to
		<u> </u>									
If there	are unme	et information	needs	how	much	does	the a	absence	of	appropri	ate
surveilla	nce data i	mpede action	?					2000100		арргорп	



What can be	done?				
				1.4	
s there a nee	ed for new researc	h in relation to	teratogen expo	sure and the rel	ated incidence
of congenital	disorders?				
f there are ur	nmet information r	needs, how mu	ch does the abs	sence of approp	riate research
data impede		,			



	ne?				
ease refer to	Tables NA1.1	in the Calculat	or and NA2 abo	ove.)	



TER-NA3 Qualitative assessment of interventions

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

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

Interventions	Coverage	Effectiveness	Cost- effectiveness	Impact
Before pregnancy			enectiveness	
Family planning, education				
Occupational health monitoring				
Environmental health monitoring				
Interventions to reduce risk				
Information on risks and exposures				
(including teratogen information				
services)				
During pregnancy				
Education on risks				
Targeted prenatal screening based				
on exposure				
Prenatal diagnosis				
Termination of pregnancy				
Maternal protection legislation				
Information on risks and exposures				
(including teratogen information				
services)				
After birth				
Newborn screening				
Newborn diagnosis				
Clinical and related interventions				
Social care and support				
Education interventions				
Compensation legislation				



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). Please enter or delete rows as appropriate.

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

Interventions	Achievable coverage	Effectiveness	Cost- effectiveness	Impact
Before pregnancy	covolugo		O I O O I I O I O O O	
Family planning, education				
Occupational health monitoring				
Environmental health monitoring				
Interventions to reduce risk				
Information on risks and exposures				
(including teratogen information				
services)				
During pregnancy				
Education on risks				
Targeted prenatal screening based				
on exposure				
Prenatal diagnosis				
Termination of pregnancy				
Maternal protection legislation				
Information on risks and exposures				
(including teratogen information				
services)				
After birth				
Newborn screening				
Newborn diagnosis				
Clinical and related interventions				
Social care and support				
Education interventions				
Compensation legislation				



TER-NA4 Quantitative assessment of interventions

The following sheets in the Calculator allow you to estimate the potential reduction in birth prevalence of congenital disorders through reducing specific teratogenic risk and prenatal screening.

Please use this section if you are interested in a specific teratogen and have data in relation to it. If you would like to consider a broad range of teratogens or you have no data, please skip this section.

>>> Go to Calculator sheet TER-Interv1

>>> Go to Calculator sheet TER-Interv2

Here, you should fill in data relating to the prevalence of specific Teratogens in different intervention scenarios: in the absence of interventions, in the current situation, and in the desired situation.

Table TER-NA3a in Calculator sheet TER-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 TER-NA3

Tables TER-NA3b to NA3g in Calculator sheet TER-NA3 refer to the current and target (desirable) situations for interventions before birth, during pregnancy and after birth. Please enter data in these tables. You may add or delete rows as appropriate.

>>> Return to Calculator sheet TER-NA3

Table TER-NA3h in Calculator sheet TER-NA3 refers to outcomes. Figures for 'current situation' come from Tables TER-NA1a and NA1b.

>>> Return to Calculator sheet TER-NA3



TER-NA5 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 TER-NA5.

Table TER-NA5SWOT diagram

Internal environment	External environment	
Strengths	Opportunities	
		+
Wooknoss	Throats	
Weakness	Threats	
Weakness	Threats	_
Weakness	Threats	-
Weakness	Threats	_
Weakness	Threats	
Weakness	Threats	
Weakness	Threats	



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

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 TER-NA6b to TER-NA6d. Start with the ground rules. Table TER-NA6b Ground rules for the prioritisation process (add rows if needed)	Now consider in the group your ground rules, prioritisation criteria and action areas, complete Tables TER-NA6b to TER-NA6d. Start with the ground rules.	(Y/N)	Accepted (Organisation represented		Person invited
Now consider in the group your ground rules, prioritisation criteria and action areas, and complete Tables TER-NA6b to TER-NA6d. Start with the ground rules.	Now consider in the group your ground rules, prioritisation criteria and action areas, complete Tables TER-NA6b to TER-NA6d. Start with the ground rules.						
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Now consider in the group your ground rules, prioritisation criteria and action areas, and complete Tables TER-NA6b to TER-NA6d. Start with the ground rules.	Now consider in the group your ground rules, prioritisation criteria and action areas, complete Tables TER-NA6b to TER-NA6d. Start with the ground rules.						
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		, and	tion areas,	teria and act	ır ground rules, prioritisation cr	ne group you	ow consider in the
Table TER-NA6b Ground rules for the prioritisation process (add rows if needed)	Ground rules for the prioritisation process (add rows if needed)		,	rules.	ΓER-NA6d. Start with the ground	R-NA6b to 7	omplete Tables TER
			reeded)	(add rows if n	les for the prioritisation process	Ground ru	able TER-NA6b



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

Table TER-NA6c	List of criteria for prioritisation of interventions (add rows if needed)
Based on your asse	essment of needs, please consider and list in Table TER-NA6d action
	OII.
Table TER-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. You may find it helpful to use decision analysis software, so as to do this in a more systematic way (see the Prioritisation document). Show your results in Table TER-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 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 TER-NA6e List of priority action areas and interventions for Teratogens

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

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



TER-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 Teratogens, the present state of interventions and the potential to improve care and reduce incidence.

	ribe the popu	lation, terato	ogens consi	idered and d	conditions a	arising fron	n exposu
the terato	gen(s)						
			_				
	ribe how the	relevant se	rvices are	organised a	and their lir	nk with ma	aternal ar
nild health	services ¹ .						
ist the ma	in services a	nd intervent	ions curren	tly available	for the ca	are and pro	eventio

Are there any threats to the continuation of services?³

¹ Possible reference section: CP2

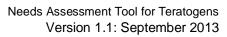
² You may wish to include an assessment of the effectiveness, cost-effectiveness, coverage, quality and level of satisfaction with the interventions or services.

toolkit Disorders	Version 1.1: September 2013
are the linmet needs as assessed by the	Toolkit2 ⁴

Vhat are the unme	needs as ass	sessed by the	e Toolkit?4	
		•		
s it feasible to mee	the identified	needs?°		

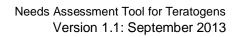
³ For example, in relation to resources, acceptability, and competing priorities.

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 and care after birth being delivered effectively, cost-effectively and according to need?; viii) Is prevention and care activities being delivered fairly (equitably)? Possible reference sections: NA3 and 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





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. Health Indicators database. Pan American Health Org (PAHO) http://ais.paho.org/phip/viz/basicindicatorbrowaser.asp
- 2. WHO Statistical Information System (WHOSIS) http://www.who.int/whosis/whostat/2010/en/index.html
- 3. Indicator definitions. (WHO) http://www.who.int/whosis/indicators/en
- 4. UNICEF country statistics http://www.unicef.org/statistics/index_countrystats.html
- 5. UN Demographic Yearbook (UNDY) series http://unstats.un.org/unsd/demographic/products/dyb/dyb2.htm
- 6. UNICEF reports on The State of the World's Children http://www.unicef.org/sowc08/statistics/statistics.php
- 7. WHO data and statistics (various links) http://www.who.int/research/en/
- 8. Global health Observatory (GHO) http://www.who.int/gho/en/index.html
- 9. Countdown to 2015 (profiles for selected countries) http://www.childinfo.org/countdown_638.htm
- 10. Health of Nations http://www.healthofnations.com/countries/map/outcomes/life
- 11. Consanguinity http://www.consang.net/index.php/Global prevalence tables
- 12. Immunisation http://apps.who.int/immunization_monitoring/en/globalsummary/countryprofileresult.cfm
- 13. UN Statistics Division http://unstats.un.org/unsd/demographic/products/socind/health.htm

Please list your own sources of data below

- 1.
- 2.
- 3.