Guide to using the Toolkit

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

Version: 1.1 September 2013

INTRODUCTION

Having completed the Getting Started document, you should now have chosen your topics, formed your project team, set out your aims and objectives, identified resources for the project, prepared a budget, allocated responsibilities, and defined the time frame for the work.

You can now begin your Health Needs Assessment. The overall process consists of:

1. Carrying out a needs assessment for each individual topic you have chosen. For each topic there is a Background Briefing, a Tool and Calculator, and a Summary Report.

    - The **Background Briefing** provides information and key references about the condition or services.
    - The **Tool** leads the user through the needs assessment process and asks for typed/written responses and simple numerical input.
    - The **Calculator** is used for entering numerical data estimates and calculations. The Tool and the Calculator must be used together – while completing the Tool, you will be asked to enter data into the Calculator.
    - The **Summary Report** within each tool sets out the main findings from your health needs assessment for the topic.

2. Considering all topics together, carrying out a **Final prioritisation and moving to planning and action** exercise to identify priorities and actions for improving the care and prevention of congenital disorders.

3. Drawing the results for all your topics and the prioritisation together in the **Final Report.**

A set of additional documents are available to assist you with your health needs assessment. These include:

Introductory Documents
- Overview Document to the PHG Foundation Toolkit for Assessing Health Needs in Relation to Congenital Disorders
- Introduction to HNA and methodology

Supporting Documents
- Ethical, legal and social issues related to treating and preventing congenital disorders
- Consanguinity – an overview of consanguinity and its implications
- Patient engagement – how patients might be engaged in managing and improving their care and in advocacy activities
- Health economics in the area of congenital disorders – an introduction
- A Glossary of terms contained in the Toolkit, to make it understandable to all

NEEDS ASSESSMENT FOR INDIVIDUAL TOPICS

The basic process for starting a needs assessment is:

Go to website → Select a region and country → Find your topic → Download files

We suggest that, if possible, users print the Tool and use the Calculator on a computer, in order to work through the process most easily. However, all the necessary documents are provided to allow you to complete the process fully on paper or fully on a computer.

Documents which are Microsoft Office file types or Open Office file types can be completed on a computer, given that software for viewing these file types are available (see below). All documents are formatted in UK English, however, it is possible that formatting may revert to these setting to those set by the user, please be aware this may occur and need to be dealt with by the user.

Notes on files provided

File downloads
If you have an unreliable or slow internet connection, we recommend that you download all files for a topic in your country in one zip file (located at the top left of the topic downloads page). This will give you all topic files, plus the generic files that are the same for all topics. Otherwise, all files are available for individual download from the pages for each topic and country.

File types
The Toolkit contains a range of file types: for completing needs assessments on paper, you can use the PDF documents. For completion on your computer you can use either the Microsoft Office files (for those using Microsoft Word and Excel) or the Open Document Format files (if you use Open Office or Libre Office in place of Microsoft Office). Some documents are only available as PDF versions, and some documents are available in all three formats. You only need to download the files that correspond to the Office Suite that you use along with the PDF-only version documents (i.e. if you use Open Office or Libre Office then download the Open Document Format versions). Libre Office is reliable, free software for completing office tasks, and can be downloaded from www.libreoffice.org. If you do not have a PDF reader, you can get one free at [http://get.adobe.com/uk/reader/otherversions].

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Using the Tool and Calculator

The exact information provided in the Tool and Calculator vary by topic. Given below is an outline of the main sections of the Tool and Calculator. For most service topics, the Calculator contents are limited to just Demography and Health Services data. (Some additional technical notes to assist you in using the Tool and Calculator are provided in the next section.)

The Country Profile (CP) (all topics; includes Calculator sheets)
This section involves completing two sheets in the Calculator: the Demography sheet and the Health-Services sheet. These are identical across topics, so if you have already entered demography or health-services information for another Needs Assessment in your population, you can copy that information into any Calculator for the same population.

Demographic factors in a population have important effects on the burden of congenital disorders. For example, maternal age and level of consanguineous marriage affect the birth prevalence of some conditions, while birth rate and contraceptive prevalence affect the absolute number of births. Maternal health and socio-economic indicators are useful for a general understanding of the target (national or sub-national) population context.

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

The Epidemiology section (E) (condition topics only; includes Calculator sheets)
This will provide the information for assessing the baseline burden of the condition in your country/territory. Using data from the Demography section and from national or sub-national data collection you will create a picture of the quantitative burden; if no specific data is available for your country, or data is thought to be of low quality, you can use the modelled estimates which are provided. In some cases you may wish to combine local with modelled data.

The Interventions section (INTERV) (condition topics; includes Calculator sheets)
For some conditions, and for some services, the Tool and Calculator allow you to estimate the effect of certain interventions on the burden of the condition.

The Needs Assessment section (NA) (all topics; includes Calculator sheets)
Following the quantitative estimation of the burden, this section will provide a systematic assessment of the policies, programmes and services that already exist in your country/territory. It will help you to consider the potential impact of policies, programmes and services that could be introduced.

The Situation Assessment (all topics)
This is a brief section in which you will consider how your political, social and economic environment improves or undermines your ability to implement desired policies and services.

The Initial Prioritisation (all topics)
This exercise will indicate what actions can best be taken to improve the prevention and care of the condition, or what actions will improve the quality of a given service, and ask you to rank the actions according to priority. Information from this section will be used in the final, overall prioritisation process (see below).

Technical notes on using the Tool and Calculator

Data estimates in the Calculators
Data for the country profile (Demography and Health Services) come from a range of sources, which are cited in brief in the sheets. Some indicators (such as density of health service personnel) are derived indirectly using two other pieces of data (in this case, numbers of health service personnel, and population numbers). For some indicators you will need to get the data locally and complete the relevant tables.

Highlighted cells in the Calculators
Some data estimates are provided with the Calculator – demographic, socio-economic and health-service data from publicly available sources, and modelled estimates of condition specific prevalence from the Modell Global Database of Constitutional Congenital Disorders. There are also cells that make automatic calculations based on data entered by users. These cells all appear with background shading – do not delete the contents of cells with shaded backgrounds, as some of these cells contain formulae that make the calculations work. You should enter data in the blank cells. It may be sensible to keep a spare, blank copy of the Calculator in case you delete any formulae by mistake.

Error indicators in the Calculator
The instructions within the Calculators assume the English convention of using as comma " , " as a separator for thousands, and a point " . " as a decimal separator. If the practice in your local language setting are different i.e. you use the comma " , " as a decimal separator then you will need to use the local language setting within the calculator.

Div/0 – this means you have the value "0" in a cell where you need a higher estimate.

#VALUE – this means you need to enter data in a previous cell in order to generate a meaningful value in this cell.

####### – this means the column is too narrow to display the number in the cell. Simply make the column wider to display the cell contents.

Weighting
Several sections of the Tool request data from research studies, surveillance systems and other data sources. If you know or suspect that the population providing data to these sources has a different burden compared to your whole country/territory population, you may want to apply weights when estimating whole-population figures from these sources. If for example a population sub-group providing data to such a source has incidence of a condition that is twice the level of the whole population, the weighting would mean multiplying the estimated prevalence by 0.5.

Example:
- Recorded incidence from surveillance data = 4.6 / 1000 live births.
- Estimated ratio of burden in surveillance data to burden in total population = 2.0 (this means surveillance data is based on a population among whom the risk of disease is twice that of the total population).
- Weight to apply to incidence from surveillance data, to give estimated incidence in total population = 1/ratio = 1/2 = 0.5.
- Estimated incidence in total population = weight x incidence in surveillance data = 0.5 x 4.6 = 2.3 / 1000 live births

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RESULTS REPORTING AND PLANNING TEMPLATE

Please use this document to bring together inputs from the Summary Reports of the individual topic chapters that have been completed in your Needs Assessment process. This may form the basis of advocacy for policy change or implementation.

FINAL PRIORITISATION

We hope that many users will conduct needs assessments for multiple clinical and service topics in their country or territory, in order to give as full as possible a picture of the health needs related to congenital disorders.

Having planned the overall needs assessment process in the Getting Started phase, and identified your overall aims and objectives, the Final Prioritisation document allows you to bring together the findings of initial prioritisations conducted within the Tool for each topic, so that you can simultaneously interpret the implications of your needs assessments for all topics. This process will indicate a range of interventions that may be appropriate in your setting, and will help you to choose a priority path of action.

Further assistance

If you have a query or want to give us any feedback about the Toolkit please email us at: toolkit@bornhealthy.org

How to cite the Toolkit

The PHG Foundation. A Toolkit for Health Needs Assessment in Congenital Disorders. Available at: http://toolkit.bornhealthy.org/. Accessed [date of access].

Please share information about the Toolkit with colleagues in your professional organisation and networks and feel free to post it on your website. The Toolkit and email support are completely free. If you would like to get regular updates about the Toolkit please email us at toolkit@bornhealthy.org.

What's new in Version 1.1 of the Toolkit?

PHGDB the database underlying the PHG Foundation Health Needs Assessment Toolkit has been updated. Demographic, health service and socio-economic indicators have been updated from publicly accessible sources. Updated epidemiological data is either from MGDB or publicly available data sources. Detailed information on epidemiological data sources and MGDB can be found in the Methods and Support documents. Given below is a summary of differences between the current and previous version of MGDB:

1. Revised estimates are for "isolated defects" as opposed to "groups" of defects. e.g. data for NTDs within the current version of MGDB relate to isolated NTDs (i.e. not those associated with other malformations) whereas in Version 1.0 of the Toolkit they

related to all non-chromosomal NTDs, including those present with other malformations.

2. The following datasets are currently unavailable due to on-going work to develop these estimates:

No. of cases by level of impairment

No/ minor disability

Moderate disability

Severe disability

Prevalence by age-group in: <1, 1-4, 5-14, 15-44 and 45+

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