



Final prioritisation and moving to planning and action

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

Now that you have worked through the individual topics and conducted the initial prioritisation exercises for each of those topics, it is time to put things together. This document enables you to prioritise actions and interventions for the overall set of conditions and services you have considered. The prioritisation process should lead to the planning and implementation of positive actions.

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PRIORITISATION OF INTERVENTIONS FOR CONGENITAL DISORDERS

You will now consider, as a single group all the conditions and services for congenital disorders that you have investigated and decide on the priority actions to address unmet needs. This should lead to the set of actions that will be most likely to tackle the burden of congenital disorders in a way that is acceptable, feasible and effective, and in accordance with circumstances (e.g. health, economic, legislative) prevailing in the target area/ population. To help this process, for each condition or health problem, please enter into Table 1 the action areas you have previously selected. Some actions may be similar as they may apply to different conditions. For all tables, please add rows or columns if necessary.

Table 1: Summary of action areas selected from previous chapters

Condition/ Service	Action area 1	Action area 2	Action area 3

Prioritisation process

Prioritisation is best done through face to face meetings involving relevant stakeholders, or alternatively by distant (electronic) communication, e.g. using the Delphi method. First you need to set up a team that will be involved in the prioritisation process. Your team may have the same members as those involved in the initial prioritisation for each specific condition or service. Alternatively, you may choose to involve a larger number of stakeholders. In any case, try to involve a representative group of people. This will enhance the validity of the process. You may involve your colleagues, experts in the field, representatives from the Ministry of Health, health services, clinical genetics networks and patients, and other stakeholders.

This exercise will lead to a decision on a hierarchy of action areas that cover all conditions and service areas. To do this first list in Table 2 the action areas for consideration (based on Table 1). You may drop some of the pre-selected items in Table 1 and may merge others, if the same type of action area has appeared more than once.

Table 2: List of action areas for prioritisation

Action area	Description

Now as a team decide your ground rules (list in Table 3) and the criteria you will use for ranking the action areas. You may use a similar set of criteria to those used in the initial prioritisation in previous chapters (see Boxes 1 and 2). Box 1 gives examples of ground rules you may wish to follow in engaging in the priority setting exercise (you may add your own rules to them). Box 2 gives examples of criteria. The criteria could be set in a brainstorming session and entered into Table 4. To have a common understanding amongst the team members, it is important to have a clear definition of each criterion set. The criteria must be mutually exclusive to avoid double counting.

Table 3: Ground rules

Empty table for ground rules

Box 1: Examples of priority setting ground rules (add or delete rows as appropriate)

1. Form the group, involving relevant stakeholders and diversity of opinions
2. List members and their responsibilities
3. Disclose conflicts of interest
4. Be transparent

Box 2: Examples of criteria used for priority setting

Relevance, feasibility (e.g. availability of resources and technology), acceptability (by target population), potential for integration with existing services, equity, potential for integration with existing services, ethical, legal and social issues (ELSI), likelihood of political and population support.

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Criteria				Overall score
	Criterion 1	Criterion 2	Criterion 3	
Weight for each criterion	0.25	0.40	0.35	
Action area 1	4	6	8	6.2
Action area 2	2	4	4	3.5

You may also wish to use a prioritisation process you are familiar with and consider adequate for this purpose. When you have decided the ranking of action, please list them in order in Table 6.

Table 6: Rank of areas for action in relation to congenital disorders (add or delete rows as needed)

Action area rank	Description
1	
2	
3	
4	
5	

PLANNING STAGE

Once priorities have been assigned to action areas, it should be possible to formulate a rational plan to accomplish the project's aim(s).

Setting the aims

Please list the aims of your programme or actions. You could refer to it as the 'born healthy programme', the 'programme to reduce the burden of congenital disorders, or by another suitable identifier.

Setting the objectives

When formulating objectives, and actions, remember to be SMART! This means having objectives which are Specific, Measurable, Achievable, Relevant and Timely (see Appendix 1 in Getting Started). Setting the objectives and outlining the strategies to achieve them also requires delegating the interventions and services to those responsible for accomplishing them, ensuring that they are adequately trained and equipped to undertake the task and setting timelines for the objectives to be achieved. You should keep this in mind.

A clear set of objectives compatible with the aim(s) and priorities can be listed, together with interventions or services necessary to achieve them. These can be placed in matrices, a simple example of which is shown in Figure 1, which takes into account that certain interventions and services will be part of achieving more than one objective. To complete Figure 1, you should start by listing and numbering the specific objectives and then listing and numbering the specific interventions and services that need to be put in place to address these objectives. For an example of general aims and associated services and interventions as they relate to congenital disorders, see Appendix 1.

Use the information in Figure 1 to populate Tables 7 and 8.

Figure 1: Planning phase (planning matrix)

		Interventions & Services							
		P1	P2	P3	P4	P5	P6	...Pn	
Objective	Obj1								
	Obj2								
	Obj3								
	Obj4								
	Obj5								
	Obj6								
	.								
	.								
	Objn								

Table 7: Specific objectives

Objectives	
1	
2	
3	
4	
5	
etc.	

Please add rows as needed

Table 8: Specific interventions and services that can address the objectives

Interventions and services	
1	
2	
3	
4	
5	
etc.	

Please add rows as needed

MOVING INTO ACTION AND EVALUATION

Based on the objectives specified above, and the associated service and intervention areas, outline what your planned actions are and briefly describe the expected results (outputs and outcomes) in relation to the items below. You may number each item to represent a different 'action', 'expected result' etc. It is also necessary to establish a monitoring or auditing process to assess both the ongoing progress and the outcomes of the changes achieved in response to the HNA. Indicators for both these processes should be set and may be linked to specific targets/milestones (time linked). Piloting the plan, or parts thereof, may be considered before full implementation.

Prevention and care before pregnancy and population wide

Actions

Expected main results of actions

Milestones

Prevention during pregnancy

Actions

Expected main results of actions

Milestones

Care and prevention after birth

Actions

Expected main results of actions

Milestones

Monitoring and auditing process

Outline how the plan will be monitored and evaluated

Detailed planning and evaluation

You may now wish to use the Planning Template to help with detailing your next steps. To achieve this, please list the specific projects that need to be carried forward in order to meet the actions you have set out above. For each of these outline the expected resources or inputs needed (e.g. health professionals, data sources, distribution of fortified food or supplements) the expected processes and outputs (e.g. numbers receiving prenatal screening, counselling, corrective or palliative operations), outcomes (changes in incidence, morbidity and mortality), and the evaluation criteria and timing of their application. Please summarise each of your projects from Table 6. You might wish to use (and adapt) the accessory tables in Appendix 2, if you find these helpful.

Project 1: Please briefly describe the project

Table 6.1: Project 1 key resources, processes, outputs, outcomes and evaluation criteria

Resources (inputs)	Processes/Outputs	Outcomes	Evaluation Criteria/time

REPEAT FOR OTHER PROJECTS!

Now it is up to you to carry the agenda forward and ensure the right actions are taken. Processes to get the outcomes you want will vary in different parts of the world, but they invariably require leadership, hard work and having the right people in place, including those who have responsibility for funding and delivering services.

Appendix 1: Example of country level aims and associated services and interventions in relation to congenital disorders.

Country level aims:

1. Recognise, diagnose, treat and rehabilitate people with congenital disorders
2. Counsel and support people with congenital disorders and their families
3. Prevent congenital disorders by:
 - a. Promoting knowledge on their risks
 - b. Improving women's, reproductive and maternal health
 - c. Reducing fetal exposure to infections, nutritional deficiencies, metabolic imbalances, environmental teratogens, drugs and alcohol
 - d. Enabling people to make choices about health and reproduction according to their personal, social, cultural and religious circumstances
 - e. Recognising and, where appropriate, screening, counselling and supporting people whose reproduction choices affect the risk of congenital disorders

Services and Interventions areas:

- Establish and provide or enhance services for the diagnosis and management of people with congenital disorders, including counselling and support for them and their families
- Establish and provide or enhance molecular, biochemical and cytogenetic laboratory services
- Establish and provide training programmes for, and enhance education of, health professionals
- Establish and provide educational programmes for the general population and for specific population groups, such as pregnant women and those of reproductive age
- Develop or enhance programmes for the promotion of women's and maternal health that are fully integrated with neonatal health programmes
- Establish and provide or enhance prenatal services including specific programmes for the screening, diagnosis and treatment of maternal infections and diseases, fetal abnormalities and rhesus incompatibility, according to local legislation and circumstances
- Establish and provide or enhance appropriate services for the screening, diagnosis and care of inherited and heritable disorders in the neonate and child
- Identify and counsel individuals who are carriers of genes that are associated with increased risk of congenital disorders in future generations

Appendix 2: Accessory tables for planning (optional)

Table A2.1: Defining resources needed

Financial	Facilities/equipment	Staff	Consumables and other

Table A2.2: Defining processes and outputs needed

Process/output	Target indicator	Linked outcome	Responsibility for delivering	Responsibility for evaluation