



Getting started: planning your needs assessment

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

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INTRODUCTION

The first steps in undertaking a Health Needs Assessment in relation to congenital disorders are to form a Coordinating Team, identify available resources for carrying out the work, set up an advisory Steering Group, choose the topic(s) for your HNA, define your aims and objectives, identify any additional stakeholders and advisers who may be involved in the project, set the time frame for the work, and prepare a budget. This 'Getting Started' document guides you through this process.

1. Forming your Coordinating Team

The Coordinating Team will take overall responsibility for the HNA, including choosing the topics, identifying financial and other resources, and carrying out the detailed work and background research. It is important to involve people with the authority both to start the HNA process and to make public health and policy decisions in light of the findings, as well as those with the technical expertise to carry out the HNA. The Coordinating Team should be supported by someone to carry out administrative/data entry and organisational functions.

List the Coordinating Team membership, identifying who will lead the team and, for each team member, their general responsibilities and how much time they will dedicate to the project. List also those providing administrative support, their time input and their functions.

2. Identifying financial and other resources

Consider the available resources for conducting the needs assessment, and where funding is coming from. This may influence what you will be able to deliver. Please list the sources of funding and resources available.

3. Setting up a Steering Group

The next step is to set up a Steering Group which will decide high level priorities, make connections, guide and provide expert input and champion the work. The Steering Group may include, for example, representation from the national (and local) Ministries of Health or equivalent institutions; the public health services; clinical and laboratory genetics; maternal and child health services; medical and health educators; patients' representatives, such as charities supporting those with congenital disorders; expertise in ethical, legal and social issues; expertise in health economics; professional societies (e.g. genetics); researchers and the private health sector. While it is important that a representative group is formed, it is best for the full group to meet only when essential, such as when a breadth of expertise and representativeness is required for the interpretation of findings, setting recommendations or decision making.

List the Steering Group membership, identifying the person who will chair the group, and the sector or stakeholder group which each member will represent.

4. Choosing HNA topic(s)

The Coordinating Team should undertake some preliminary work to develop the list of priority topics for needs assessment. In this phase you should consider the whole range of topics. Through discussion, advice (for example, from your Steering Group) and, where necessary, further initial research, you should produce a list of topics that you have considered and agreed will or will not be the subject of HNA, and set out the evidence on which your decision was based. This will help you to justify the work that you are about to undertake.

Below is an initial exercise that helps you to identify the topics that are most important for your country or region, and gives you the opportunity to make your reasons for choosing these topics transparent and explicit. We recommend that you complete this section even if you already have a clear idea about which conditions or services you intend to focus on, as it will enable you to take an inclusive approach from the outset and make a stronger case for policy action.

The topics included in the Toolkit are:

Clinical topics:

- Congenital heart disease
- Congenital hypothyroidism
- Congenital syphilis
- Down's syndrome
- Fetal alcohol spectrum disorder
- G6PD deficiency
- Neural tube defects
- Orofacial clefts
- Rhesus haemolytic disease of the newborn
- Congenital rubella syndrome
- Sickle cell disease
- Thalassaemia

Service topics (or opportunity for interventions):

- Health services
- Teratogens
- Preconception care and screening
- Prenatal care and screening
- Newborn screening

There are various criteria you can use to inform your choice of topics. These include:

- which conditions represent a significant burden of disease in your country
- which risk factors for congenital disorders are significant in your country
- whether there are any particular services, or interventions that influence outcomes, that you think are significant in your country.

The following sections will guide you through the process of choosing topics on the basis of these criteria. For each topic, you should also consider the target population of the HNA; this will usually be the whole country population, but may be restricted to a specific geographical area

within the country or a distinct subgroup of the population defined by certain characteristics, such as ethnicity or poor access to services.

4.1 Choosing your topics based on burden of disease

You may have information on the burden of disease in your country. If not, general information on the burden of congenital disorders in different regions of the world may be found in the *Overview document to the PHG Foundation Toolkit for Assessing Health Needs in Relation to Congenital Disorders*. Figures 1 and 2 in that document show the global distribution of births potentially affected by genetic disorders or congenital malformations. The documents referenced in the Overview provide some further detail. As a more thorough (but time-consuming) exercise you can consult the Background briefing documents for the conditions included in the Toolkit. These documents summarise, where available, the data relevant to your country.

List any congenital disorders that represent a significant burden of disease in your country or region, specify the relevant population, and reference the evidence for including each condition.

List also the other conditions that you have considered and decided are not a significant problem or not a priority for further work in your country, and your reason for not choosing each condition.

4.2 Choosing your topics based on risk factors

Table 1 gives some examples of risk factors that you may wish to consider. Please add further rows to the Table if you are aware of other risk factors in your country or region that are not included here.

Table 1: Some risk factors associated with congenital disorders included in the PHG Foundation Toolkit

Risk factor	Related HNA(s) in the PHG Foundation Toolkit
Malarial region (or population originating from malarial region)	Sickle cell disease Thalassaemia G6PD deficiency
Advanced maternal age	Down's syndrome
Customary consanguineous marriage	Recessive genetic diseases (including sickle cell disease and thalassaemia)
Sub-optimal maternal nutrition (particularly folate or iodine deficiency)	Neural tube defects Orofacial clefts Congenital heart disease Congenital hypothyroidism
Industrial or agricultural pollution	Teratogens
Sexually transmitted diseases	Congenital syphilis
No, or inadequate, rubella immunisation	Congenital rubella syndrome
Alcohol abuse	Fetal alcohol spectrum disorder

List relevant risk factors, and associated HNA topics, for your country or region, and specify the relevant population.

Risk factor	HNA topic(s)	Target population

List also the risk factors that you have considered and decided not to include.

4.3 Choosing your topics based on determinants of outcomes

Finally, you may wish to approach your choice of topics by focusing on determinants of outcomes for the care and prevention of congenital disorders in your country or region. Table 2 lists some factors you may include for consideration. Please add further rows to the table if you are aware of other determinants of outcomes that are significant in your country or region. You may find it useful to consult representatives of patient support groups, who may have views on the adequacy or otherwise of existing services and interventions.

Table 2: Determinants of outcomes for congenital disorders, and related health needs assessments available in the PHG Foundation Toolkit

Determinant of outcomes	Related HNAs in the PHG Foundation Toolkit
Maternal health before and during pregnancy	Health services Preconception care and screening Prenatal services Neural tube defects Orofacial clefts Fetal alcohol spectrum disorder Teratogens Congenital syphilis Rhesus haemolytic disease of the newborn
Infectious disease control	Preconception care and screening Prenatal care and screening Congenital syphilis Congenital rubella syndrome
Food fortification	Neural tube defects Orofacial clefts Congenital hypothyroidism Preconception care and screening
Occupational and environmental health legislation	Teratogens Preconception care and screening
Prenatal care and diagnosis	Prenatal care and screening Sickle cell disease Thalassaemia

	Down's syndrome Neural tube defects Congenital heart disease Rhesus haemolytic disease of the newborn
Early diagnosis of congenital disorders	Health services Newborn care and screening G6PD deficiency Sickle cell disease Congenital hypothyroidism
Paediatric surgery	Health services Orofacial clefts Neural tube defects Congenital heart disease
Learning support	Down's syndrome Congenital hypothyroidism Fetal alcohol spectrum disorder
Physiotherapy and rehabilitation	Health services Congenital heart disease Orofacial clefts

List important determinants of outcomes, and associated HNAs for congenital disorders, for your country or region. (If applicable, also specify the target population for the HNA.)

Determinants of outcomes	HNA topic(s)

Now list all the topics you have identified as a result of considering the burden of disease, risk factors, and determinants of outcomes for congenital disorders in your country or region. Assign a priority to each of these topics, on a scale of 1 to 5, where 1 is the highest priority and 5 is the lowest. (You may also wish to note at this stage your reasons for prioritising; for example, burden of mortality or morbidity, whether there are experts available, tackling inequalities between different populations, political imperative or feasibility.)

HNA topic	Priority	Reason for assigning priority
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Considering these priorities, and the resources you have available, make a final list of the HNA topic(s) you have chosen, including the target population for each.

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5. Clarifying aims and objectives

Having chosen your topics, and based on initial information and your evaluation (including expert opinion), what are the main issues in relation to congenital disorders that you will be likely to address in your HNA? For example, you may wish to use the HNA as a first step towards decreasing health inequalities between different regions or social/ethnic groups, or to assess the need for a completely new service (for example, a preconception health service).

For each topic you have chosen and, if possible/relevant, considering your chosen set of topics as a group, describe the scope and aims of your HNA (explain why you have chosen those topics, whether/how they are linked to each other, and what you hope to achieve as a result of the HNA).

Now set out your specific objectives, keeping in mind that objectives should be SMART (Specific, Measurable, Achievable, Realistic and Timely; see Appendix 1 for further details on setting objectives).

Keep in mind what the HNA is for: In general the HNA enables the identification of needs and interventions to address unmet needs and reduce inequalities, leading to improved health and health care. It is used to inform decisions according to health need, on investment/ allocation of resources, prioritisation, planning, commissioning and delivery interventions, programmes and services.

6. Identifying additional stakeholders and expert advisers

In addition to the formal members of your Coordinating Team and Steering Group, there is likely to be a wider group of people who need to know about and contribute to the work, but whom it is not necessary or practical to involve as key players in the process. These people may include health professionals and other interested parties, as well as clinical experts and patient representatives for the specific topics you have chosen. Some of these people may be co-opted to join subgroups to advise on specific issues as the work progresses.

List any additional stakeholders whom you will inform about the HNA.

List any clinical experts or patient representatives who may be invited to advise on or be involved in work on specific topics.

Use this space to list confirmed participants.

7. Defining the time-frame and responsibilities

Specify a time for each activity and milestones to be achieved. For example, for each topic you have chosen you may include steps such as forming expert subgroups, and working through the HNA tool and calculator, which will include data gathering and interpretation, consultation with experts, scheduled evaluation meetings, preparation and presentation of reports. Allocate specific responsibilities to Coordinating Team members.

8. Preparing the budget

Consider the activities necessary to complete the needs assessment, and the costs associated with each. You should consider the relationship between your expenditure and the financial resources identified above.

Prepare a detailed budget.

You are now ready to begin your HNA for the set of topics you have chosen. For instructions on how to go about this, please refer to the Conducting a Health Needs Assessment: a Guide to Using the PHG Foundation Toolkit.

Please contact the PHG Foundation (toolkit@bornhealthy.org) for any questions and to send your comments and feedback.

APPENDIX 1 : SMART OBJECTIVES

Objectives should be realistic targets for the programme or project. Think of them as helping you to answer the question: WHO is going to do WHAT, WHEN, WHY and TO WHAT STANDARD.

SMART stands for Specific, Measurable, Achievable, Realistic and Timely.

- Specific – The programme states a specific outcome or a precise objective. This should be stated in numbers, percentages, frequency or similar numerical form. You should have defined your terms and used appropriate language that everyone can understand.
- Measurable – The objective can be measured and the way of measuring it is identified and defined.
- Achievable – Can you get it done in the proposed timeframe and in this political climate for this amount of money?
- Realistic – Who is going to do it? Do they have the necessary skills and resources, and who carries responsibility?
- Timely – Setting deadlines: when will we accomplish the objective?

Example of a SMART outcome objective from the March of Dimes (Hawaii chapter):

“By December 31st, there will be a 70% decrease in the number of babies born prematurely or of low birth weight to program participants.”

This link gives you a handy ‘ten steps to setting SMART objectives’ from the National Primary and Care Trust in the UK.

<http://www.natpact.nhs.uk/uploads/Ten%20Steps%20to%20SMART%20objectives.pdf>