

# Technical Consultation on Folate Status in Women and Neural Tube Defect Risk-Reduction

## CONCEPT NOTE

**Lead organization:** Micronutrient Forum

**Title:** Technical Consultation on Folate Status in Women and Neural Tube Defect Risk-Reduction

**Context:** Many countries have made progress in reducing child mortality from infectious diseases like malaria and HIV. As a result, other causes of child mortality are becoming increasingly important, with birth defects (a.k.a. congenital anomalies) now becoming a leading cause of morbidity and under-five mortality in many countries. For this reason, further improvements in child survival will depend on the ability to prevent birth defects.

Reducing the risk of neural tube defects (NTDs) represents a significant and feasible opportunity to decrease the toll of birth defects globally, for several reasons. NTDs, which include spina bifida and anencephaly, are among the most serious and most common congenital anomalies (WHO, 2015). NTDs affect the development of the brain and spine, and can lead to early death and lifelong disability. As a group, NTDs may constitute approximately one-tenth of all congenital anomalies worldwide and are one of the top three largest congenital burdens (Blencowe et al., 2010).

A large fraction of NTDs are preventable through relatively simple nutritional interventions, based on improving folate status in the population. Supplementation and population-level mandatory fortification of staple foods that include folic acid have been effective in countries where they have been widely implemented. The overall goal of these interventions is to help women consume the recommended amount of folic acid prior to and during early pregnancy, for NTD risk-reduction (WHO, 2015). However, implementing these interventions globally has proven challenging, mainly due to significant gaps in knowledge of folate status of women and capacity to evaluate the effectiveness (and safety) of interventions aimed at reducing the incidence of NTDs.

### **Rationale for the consultation:**

- Global data are lacking: Current data on NTDs and folate status are lacking. Effective birth defects surveillance is largely absent among the world's most vulnerable populations. Most available data are based on model estimations, rather than local data. Folate status among women of childbearing age is virtually unknown in countries with vulnerable populations. There is an urgent need to develop systems and track these data to help guide investment in implementation efforts.
- Obstacles and challenges to deliver folic acid to populations remain: Insufficient folate intake can have a direct impact on NTD prevalence, if blood folate concentrations among women of reproductive age are not high enough for NTD risk-reduction. (WHO, 2015). Because NTDs develop very early in pregnancy, when most women are not aware they are pregnant, reducing the risk of NTD affected-pregnancies will require supplementation with folic acid on a daily basis, and population-based mandatory fortification of staple foods. However, although policies might exist, few countries have implemented these interventions at large scale and in a sustained manner. Countries with the highest expected burden are not among them. Additionally, it is important to ensure the safety of folic acid intervention programs.
- Innovations are needed: Better low-cost, field friendly methods are needed to assess folate status, deliver interventions for NTD risk-reduction, and monitor NTDs and other outcomes. These innovations are crucial especially where the burden is high and the need great.

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**Objective of the technical consultation:** To develop a road map to better inform and prioritize investments in NTD risk-reduction; to help guide implementation efforts in terms of feasibility of interventions and the potential for acceleration; and to identify the knowledge gaps that remain including addressing any questions on safety and efficacy of folic acid interventions.

**Key technical issues to be addressed:**

- I. Folate status (inadequacy/deficiency) (Review of recommended biomarkers of folate status, as per BOND group, and relation to risk of NTDs.)
  - a. Global prevalence of folate inadequacy/deficiency
  - b. Risk factors for folate inadequacy/deficiency
  - c. Global incidence of NTDs (anencephaly and spina bifida)
  - d. Risk factors for NTDs
  - e. Estimated impact (i.e., percent of NTD reduction) given different interventions and coverage scenarios)
- II. Fortification
  - a. Reach/coverage
  - a. Vehicles for high risk areas (innovations beyond cereal grains)
  - b. Safety questions
  - c. Desirability and opportunity/availability of including Vitamin B12
- III. Investment
  - a. Key success factors for implementation
    - i. Cost-effectiveness
    - ii. Readiness to scale-up/accelerate
  - b. Prioritization framework to identify best opportunities for investments
    - i. Burden
    - ii. Tracking effectiveness and safety of interventions
    - iii. Implementation options
    - iv. Platform to advance action

**Strategy:**

- Formation of an independent, knowledgeable and unbiased committee.
- Conduct of two in-person committee meetings where the committee will consider the magnitude of the problem, knowledge gaps, interventions, harmonization, and the pros, cons and challenges of different methodological approaches to risk-reduction.
- Development of a road map for global action.

**Committee composition:** The committee would consist of 8-10 experts who offer differing perspectives in areas where there is still debate and are multidisciplinary in scope, including representatives from nutrition, epidemiology, public health, private sector, and economics.

**Expected output:** Development and dissemination of a final scientific report (i.e., the road map) to reflect consensus or diversity of opinion of the conclusion of the committee.

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**References:**

- Blencowe H, Cousens S, Modell B, Lawn, 2010. Folic acid to reduce neonatal mortality from neural tube disorders. *International Journal of Epidemiology*. 39,i110-i121.
- World Health Organization, 2015. Data from WHO Statistics Website  
<http://apps.who.int/gho/data/view.main.CM3002015REG6-CH15?lang=en> Accessed on September 22, 2016.
- World Health Organization. 2015. Guideline: Optimal Serum and Red Blood Cell Folate Concentrations in Women of Reproductive Age for Prevention of Neural Tube Defects. Geneva: World Health Organization.