

## Executive Summary

**Research Project:** An evaluation of thalassemia prevention and control in pregnancy program

In Thailand, approximately one percent of the population is affected by thalassemia and it has been reported that about 40% of the population carry at least one of the abnormal genes. Clinical severity can range from fetal demise and early neonatal death to poor quality of life. Patients affected by this chronic condition often suffer financial hardship due to high treatment expenses. The Ministry of Public Health introduced the National Thalassemia Action Plan 2007-2011 with the aim to reduce the number of newborns with severe thalassemia and to improve patients' quality of life. Later, the National Health Security Office (NHSO) also implemented a strategic plan for prevention and control of thalassemia 2014-2016 called Thalassemia Prevention and Control in Pregnancy Program. However, the results of the program revealed that its performance was poorer than expected. In 2018, Health Intervention and Technology Assessment Program (HITAP) was commissioned by NHSO to evaluate the Thalassemia Prevention and Control in Pregnancy Program. The objective of this study was to assess the outputs, outcomes, supporting factors, challenges, and implementation barriers of the program.

This study employed both quantitative and qualitative approaches using data collected from June to November 2018 within eight provinces of Thailand that were purposively selected. Quantitative data on health services utilization for prevention and control of thalassemia in pregnant women and their partners was collected from Provincial Public Health Offices and hospital information systems. Additionally, incidence and prevalence data were collected from in-patient and out-patient reimbursement databases from NHSO in fiscal years 2012-2017. For qualitative data, information on supporting factors, challenges, and barriers for the implementation of the Thalassemia Prevention and Control in Pregnancy Program were obtained from document reviews and in-depth interviews with key informants. In total, there were 130 informants comprising policymakers; relevant government officers at regional and national levels; health care providers at district, provincial and regional levels; and health services recipients.

The evaluation focused on outcomes and outputs, governance, and service provision, as follows:

**Outputs and outcomes of the Thalassemia Prevention and Control in Pregnancy Program:** an analysis of thalassemia prevention and control services utilization using data from Provincial Public Health Offices in 6 provinces during fiscal years 2016 and 2017 indicated that between 83.7- 99.8% of all new pregnant women who received antenatal care also had access to thalassemia screening services. Further, about 60.7-86.7% of men whose partners had positive results had access to thalassemia screening services. Between 28.8- 87.4% of couples at risk of having a newborn with severe thalassemia received prenatal diagnosis. Eventually, 34.6-100.0% of proven severe fetal thalassemia cases underwent a termination of pregnancy.

An analysis of individual data retrieved from eight public hospital databases in fiscal year 2017 illustrated that newly pregnant women had access to thalassemia screening services within a minimum of 9.7 weeks and maximum of 17 weeks of gestation during the first antenatal care. Additionally, women underwent thalassemia confirmation processes by Hb typing and  $\alpha$ -thalassemia 1 at an average gestational age of less than

15 weeks and 17 weeks, respectively. Furthermore, an analysis of in-patient and out-patient reimbursement databases from NHSO showed that the prevalence of severe thalassemia has increased every year from 14 cases per 100,000 population to 23 cases per 100,000 population in fiscal years 2012 and 2017, respectively. The incidence of severe thalassemia in children (0-4 years old) has declined from 20 cases in 100,000 population to 19 cases in 100,000 population in fiscal years 2016 and 2017, respectively.

**The governance system of the prevention and control program:** the long-term prevention and control program has made the thalassemia implementation as a part of the routine works. A number of thalassemia patients were not prioritized in several provinces as their problem was not seen as major or urgent. Further, thalassemia was not included in the core key performance indicators of the Ministry of Public Health (MoPH). These factors led to the following problems: a lack of systematic monitoring and evaluation, and inadequate financial support for staff capacity building as well as the development of media materials to be used for health services recipients/ public education. Additional problems included translating policies into practice, miscommunication among relevant personnel, and a lack of proper coordination across and within organizations - resulting in a misunderstanding of the implementation of such policies among health personnel. Moreover, the information system of thalassemia was considered as redundancy and the current reimbursement policy does not cover certain thalassemia-related service expenses, in which case recipients or hospitals may need to absorb expenses incurred.

**Service provision for the prevention and control of thalassemia in pregnant women:** a common problem in providing services was that partners did not turn up to their screening test, hence, “couples at risk” could not be confirmed. Furthermore, pregnant women and obstetricians in many hospitals refused to perform prenatal diagnosis and abortion for severe fetal thalassemia. Delayed attendance for antenatal care was also one of the barriers for pregnant women in receiving prenatal diagnosis and termination. Several problems related to service providers were identified: inadequate number of service providers, lack of confidence in counseling, and lack of standard practice guidelines for counseling. Moreover, limited capacity of health care facilities in confirming severe thalassemia cases resulted in specimen or patient referral to health care facilities with more capacity. In some cases, the referral could lead to delays in reporting test results, hence, hindering pregnant women from taking other necessary tests in a timely manner. However, this study found that health care providers in every province used a new means of communication, i.e. Line application to facilitate the coordination between health care providers in other facilities as well as between health care providers and pregnant women. As a result, the process of reporting test results was expedited, especially for following up on test results from a laboratory.

**Thalassemia service recipients and local context:** most pregnant women acquired basic knowledge relating to characteristics of thalassemia and its screening process from nurses at antenatal care (ANC) clinics during the first ANC appointment. However, some women reported an inadequate understanding of

thalassemia. Notably, the majority of pregnant women did not know that they are entitled to free-of-charge antenatal care and thalassemia screening services, indicating that the rights to health services related to the prevention and control of thalassemia were not well-known to most pregnant women. Their decision to seek thalassemia prevention and control services were dependent on many factors, including the level of comprehension of the disease, beliefs, culture, existing general knowledge, and suggestions from health care providers.

### **Policy recommendations**

#### ***Organizations at national level***

Department of Health, Department of Medical Sciences, and National Health Security Office should jointly develop systems or channels to facilitate communication between organizations at national and regional levels, and health care providers. This includes policy and feedback communication from national and regional organizations to organizations at the operational level and vice versa.

Department of Health and National Health Security Office should jointly develop a thalassemia database to be used for monitoring and evaluation in order to improve policy implementation. This database could be further developed from the existing NHSO-prenatal screening integration system.

Department of Health and National Health Security Office should continuously monitor and evaluate policy implementation at the national level through the database mentioned in recommendation number 2.

National Health Security Office should periodically update the financial compensation rate for thalassemia-related laboratory tests to capture the current expense which can be higher than the reimbursement rate provided by NHSO, such as laboratory tests for beta mutation analysis and transportation costs.

Department of Health, Department of Medical Sciences, National Health Security Office, and Thalassemia Foundation of Thailand should support relevant organizations at the regional level to build capacities on academia and standard practice guidelines.

Department of Health should develop guidance for thalassemia counselling from the first point of contact (antenatal care) to the end (in the case of termination of pregnancy), as well as provide materials used in the counselling process.

Department of Health and relevant organizations should promote the campaign “the first contact before 12 weeks’ gestation”, knowledge on thalassemia, and the right to health services to the general population through various channels.

#### ***Organizations at regional level***

Maternal and Child Health Board at health regional or provincial levels should regularly monitor and evaluate the implementation of thalassemia prevention and control policy at health regional and provincial levels through the database mentioned in recommendation number 2.

Regional Health Promotion Centre, Regional Medical Sciences Centre, National Health Security Office at regional level, and Maternal and Child Health Board at health regional or provincial levels should jointly organize workshops on academic matters and standard practice guidelines ( supported by relevant

organizations at the national level) for a multidisciplinary team, especially when there are changes in practice guidelines.

Maternal and Child Health Board at health regional, and provincial levels, and central/general hospitals in each province should jointly consider the capacities of health facilities at different levels (within each area) in providing thalassemia prevention and control services. They should collaboratively set up referral and reporting systems and consider the expansion of health facility capacities (if necessary) in providing services such as confirmation tests, prenatal diagnoses, and pregnancy termination. However, this expansion depends on the availability of budget and human resources as well as cost-effectiveness.

For more information: <http://www.hitap.net/documents/174625>