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The Urgency of Screening for Thalassemia Carriers in Indonesia: Policy Analysis

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ABSTRACT

Thalassemia is a hereditary blood disorder that, while incurable, is entirely preventable through early detection. In Indonesia, an estimated 6–10% of the population carries the thalassemia gene but screening is not a nationwide mandatory. Existing initiatives remain fragmented across regions and target only specific groups, such as prospective brides and grooms in Jakarta or pilot programs in Bekasi Regency. Lack of early screening leads to the birth of thousands of children with thalassemia major, requiring lifelong transfusions and iron chelation therapy that costs the government IDR 800 billion per year. To achieve long-term sustainability, Indonesia must shift from curative to preventive strategies by integrating genetic screening into the national health insurance and reproductive health systems. Policy Ask: Develop a joint regulation between the Minister of Health and the Minister of Religious Affairs, or Minister of Health Regulation (Permenkes), mandating premarital and school-based thalassemia screening as part of national health and marriage registration programs.

INTRODUCTION

Thalassemia is known to be the most common genetic disorder in the world, with approximately 7% of the global population being carriers. It is categorized into thalassemia major (which requires lifelong blood transfusions), thalassemia intermedia (which requires occasional transfusions), and thalassemia minor (which is asymptomatic and does not require transfusions). A person develops thalassemia by inheriting the gene from both parents. If only one parent carries the gene, the child becomes a carrier without showing symptoms (Eleftheriou & Angastiniotis, 2021; Tubman et al., 2015). Each year, between 300,000 and 500,000 newborns worldwide are born with severe hemoglobin disorders, leading to 50,000 to 100,000 deaths from β-thalassemia. Developing countries like Indonesia account for about 80% of these cases (Eleftheriou & Angastiniotis, 2021).

Indonesia is located within the global thalassemia belt, with a beta thalassemia gene frequency ranging from 3-10%, according to epidemiological studies (Kemenkes, 2018). This means that 6-10 out of 100 people in the country are thalassemia carriers (Anggraini et al., 2018). This number is rising; the Indonesian Thalassemia Foundation (YTI) reported 1412 cases in 2008, which increased sevenfold to 9131 in 2018. As of June 2022, there were 10,973 people with thalassemia in Indonesia (Kemenkes, 2018; Kemenkes RI, 2021).

As the number thalassemia case continues to grow, so do the costs associated with their treatment. The government of Indonesia provides ongoing supportive management for thalassemia patients, including lifelong blood transfusion and iron chelation therapy, as outlined in the Decree of the Minister of Health of the Republic of Indonesia No. HK.01.07/MENKES/1/2018 on National Guidelines for Medical Services (PNPK) for Thalassemia Management (Kemenkes, 2018). The annual cost of one-year blood transfusion and iron chelation therapy for one 20-kg child with thalassemia disease can reach IDR 300,000,000 (Kemenkes, 2018), making thalassemia one of the fifth most expensive disease managed by the country.

However, this combined treatment is not without implications. Blood transfusion, although common, can lead to transfusion reactions and various diseases. Additionally, repeated transfusions result in iron buildup in all organs in the body, which may lead to heart failure and physical growth issues (Kemenkes, 2018; Mediani et al., 2022), particularly malnutrition (Thalassaemia International Federation, 2021). In addition to physical problems, multiple treatments of thalassemia can cause psychosocial disorders. Patients often feel insecure about their shorter physical height and late or no puberty compared to their peers. As

they age, concerns about future career and life often shadow thalassemia patients. Studies reported that around 80% of patients with thalassemia major experience at least one psychiatric disorder, primarily depression during prepuberty and puberty stages. This condition often gets worse due to frequent hospitalizations, high treatment costs, and insufficient family support (Aldwaik et al., 2021; Xu et al., 2021).

This recessive nature of thalassemia underscores the importance premarital screening to prevent the birth of children with thalassemia major. The International Federation of Thalassemia advocates for public awareness campaigns of thalassemia as the primary preventive strategy (Thalassaemia International Federation, 2021). The World Health Organization (WHO) also recommends thalassemia carrier screening and prenatal diagnosis as two key preventions of thalassemia (Eleftheriou & Angastiniotis, 2021). Unfortunately, public awareness for thalassemia prevention in Indonesia is still low, particularly among 58.5% parents (Anggraini et al., 2018), leading to inconsistent participation in premarital screening to prevent thalassemia in an unborn child. Those who oppose such screening generally lack understanding about the genetic nature and traits of thalassemia. Moreover, they may view the screening as offering no immediate benefits, causing families to focus on pressing health issues like immunization, stunting, and malnutrition rather than rare genetic diseases (De Jaka et al., 2019; Utami & Kusumaningrum, 2020). Although there are regulations and guidelines in place for screening, it is not mandatory for couples to have it before marriage (De Jaka et al., 2019; Kemenkes, 2018).

Despite growing awareness and several regional initiatives, Indonesia still lacks a comprehensive national policy framework that integrates thalassaemia prevention into both the health financing system and reproductive health regulations. This gap results in fragmented implementation, inconsistent screening coverage, and minimal budget allocation for prevention at the national level.

This policy brief aims to identify existing policy gaps and propose actionable, cross-sectoral strategies, particularly through stronger coordination between the Ministry of Health, the Ministry of Religious Affairs, and local governments, to institutionalize nationwide thalassaemia screening and ensure sustainable financing through the National Health Insurance (JKN) scheme.

EXISTING POLICIES

National Policies legal framework, clinical standards, and management of thalassemia

a. Law of the Republic of Indonesia Number 17 of 2023 (Republic of Indonesia, 2023) on Health regulates the implementation of promotive, preventive, curative, and rehabilitative health efforts.
b. Presidential Regulation Number 64/2020 on National Health Insurance (JKN) ensures the sustainable support and benefits from JKN for thalassemia patients, covering the outpatient care, hospitalization, blood transfusion, and iron seaman.
c. Decree of the Minister of Health HK.01.07/MENKES/1/2018 concerning the PNPK for Thalassemia Management serves as a clinical reference and the standard of thalassemia services in health facilities, emphasizing the need for thalassemia carrier screening as part of a comprehensive service.
d. The Thalassemia Control Guidelines–compiled by the Directorate of Prevention and Control of Non-Communicable Diseases of the Directorate General of Disease Prevention and Control of the Ministry of Health in 2022–include primary services for early detection, referral, education, and prevention.

Regional Policy

a. Jakarta
   Regulation of the Governor of Jakarta No.185/2017 concerning Counseling & Health Examination for Prospective Brides and Grooms provides operational guidelines for the relevant sectors for the implementation of premarital counseling & health checks.
b. Bekasi Regency
   The Regulation of Bekasi Regency No.1/2019 concerning the Optimization of Health Services for Persons with Thalassemia posits to support local healthcare services and financing, as well as regulating healthcare membership, benefits & types of services, fund management, and service optimization providers for people with thalassemia.
c. Surabaya City
   The Instruction of the Mayor of Surabaya No.1/2023 concerning the Health Office and Public Health Centre to carry out premarital examinations and reproductive health counseling for prospective brides and grooms and to issue examination letters.

While national and regional regulations concerning thalassaemia screening exist, coordination between national and subnational levels remains limited. Local governments such as Jakarta, Bekasi, and Surabaya have developed promising initiatives but lack of systematic evaluation and mechanism to ensure alignment with national policymaking. Strengthening intergovernmental coordination and harmonizing policy implementation are therefore essential for the scale-up of thalassaemia prevention programs across Indonesia.

Table 1. Policy Gap and Challenges

Policy Level	Strengths	Challenges
National	Legal basis through Law No. 17/2022, JKN, and PNPK Thalassemia Guidelines.	Lack of operational framework for coordination with the Ministry of Religious Affairs and subnational governments.
Regional (Jakarta, Bekasi, Surabaya)	Active implementation of premarital screening programs.	Unequal enforcement, limited evaluation, and insufficient funding.
Cross-sectoral	Growing awareness among policymakers.	No integrated database or consistent monitoring mechanism.

PROBLEM IDENTIFICATION

The growing number of people living with thalassaemia in Indonesia reflects a complex set of systemic, financial, and sociocultural challenges rather than a single policy gap. Although the prevalence of carriers is estimated at 6–10% of the population, screening remains inconsistent and fragmented, depending largely on regional government initiatives rather than a national mandate.

Limited preventive financing is one of the major constraints. The National Health Insurance (JKN) primarily covers curative services, while preventive screening is either funded by local budgets or borne by individuals, leading to unequal access across regions. In addition, the absence of an integrated national registry for thalassaemia carriers results in poor data harmonization between laboratories, health facilities, and policy units, making it difficult to monitor screening coverage and outcomes.

Beyond structural issues, deeply rooted sociocultural and religious factors continue to shape public attitudes toward genetic screening. Misconceptions about heredity, fear of stigmatization, and limited understanding of carrier status often discourage individuals and families from participating in premarital or adolescent screening. In certain communities, screening is perceived as morally or religiously sensitive, as it may raise concerns about marriage eligibility or family honor.

These interlinked challenges indicate that the core problem is not only the lack of screening availability but also weak preventive financing, fragmented data systems, and cultural barriers that hinder the adoption of preventive health behaviors. Addressing thalassaemia, therefore, requires empathetic, community-based approaches that respect religious values while promoting health literacy and equity in access to preventive services.

URGENCY OF THE PROBLEM AND DISCUSSION

Thalassemia is an incurable but preventable hereditary disease. The thalassemia management program provides optimal treatment to promote growth and development in thalassemia patients, especially those with thalassemia major. However, thalassemia management in Indonesia is limited to blood transfusions and iron chelation because definitive measures like bone marrow transplantation and hematopoietic stem cell therapy are generally expensive and beyond the reach of people from low socioeconomic statuses. Therefore, preventive measures through population screening are the most recommended approach in the country (Wahidiyat et al., 2020).

The National Health Insurance policy implemented through the Indonesian Social Security Administrator for Health (BPJS Kesehatan) posits that the government will finance the costs incurred for thalassemia management, which amount to IDR 300 million per patient weighing 20 kg. This amount equals to screening cost for 750 people, or IDR 400,000–500,000 each, that covers hematological testing, including mean corpuscular volume (MCV), mean corpuscular hemoglobin (MCH), and hemoglobin electrophoresis. These costs do not include molecular DNA analysis, which is generally reserved for confirmatory testing among couples identified as high-risk carriers.

Currently, Indonesia does not have a national registry for thalassemia carriers, although efforts are being made to integrate data through the *SatuSehat* national health platform developed by the Ministry of Health. This platform aims to connect laboratory, hospital, and population health data. Meanwhile, regional pilot programs in cities like Jakarta, Bekasi, and Surabaya have shown promising early results, including increased awareness among prospective couples and improved detection rates for carriers. However, there is a lack of formal national evaluations to assess long-term impacts or cost-effectiveness, highlighting the need for standardized monitoring and evaluation in any future nationwide implementation. Additionally, while the costs of preventive programs remain relatively stable, the costs of medical treatment are rising each year.

Recent administrative data indicate that the national health insurance (JKN) continues to incur significant expenses related to thalassemia. In 2024, BPJS Kesehatan paid for about IDR 800 billion worth of care (IDR 716.9 billion for outpatient care and IDR 184.3 billion for inpatient care). By March 2025, it is expected to pay for an additional IDR 165 billion. These figures underscore the ongoing high curative burden. Indonesia's Health Profile 2023 also highlights extensive utilization and expenditures for thalassemia services, reinforcing the need for a prevention-focused strategy (Kemenkes RI, 2023).

Investment in prevention remains limited. Official monitoring reveals that promotional and preventive expenditures accounted for only about 0.5% of JKN's total benefit outlays in late 2024, indicating that the program is still primarily curative. The Ministry's 2024 performance report indicated that preventive spending made up 12.5%, which is still below the 15% target set by policy. By strengthening front-loaded preventive investments, like nationwide screening, Indonesia could enhance fiscal sustainability and lower long-term curative costs.

The government finances promotive, preventive, curative, and rehabilitative measures. Thalassemia prevention includes health campaigns, carrier screening, premarital genetic counseling, and prenatal diagnosis, aimed at reducing the number of babies born with thalassemia major (Kemenkes, 2018). According to 2021 data from the Ministry of Health, the majority of the BPJS Kesehatan budget was allocated to curative treatments, while promotional and preventive programs received only 0.3% of the total health budget (Kemenkes RI, 2023).

Many countries have reported success in reducing new cases of thalassemia through prevention programs. For example, Cyprus launched a national prevention initiative in 1983 that combined mandatory premarital screening and prenatal diagnosis, achieving zero new cases by 2000 (Kleanthous, 2019). Sardinia, Italy, introduced health education and school-based population screening that reduced new cases from 120 to just 3–5 per year (Monni et al., 2018). Thailand integrated carrier screening into antenatal and school health programs, significantly lowering the birth rate of affected babies (Paiboonsukwong et al., 2022; Ratanasiri et al., 2006).

While these models show impressive success, Indonesia's sociocultural and religious context necessitates careful adaptation. Some practical components to consider include:

1. Implementing school-based screening, based on the Sardinia and Thailand models, which could fit within Indonesia's Usaha Kesehatan Sekolah (UKS) program.
2. Establishing mandatory premarital screening and counseling, inspired by Cyprus, which could be carried out through the Ministry of Religious Affairs using its existing authority for premarital health examinations.
3. Launching comprehensive anti-stigma and public education campaigns, in partnership with religious and

community leaders, to promote cultural acceptance of genetic screening.

In Indonesia, cultural and religious beliefs limit pregnancy termination, making population-based carrier screening and informed counseling before marriage or starting a family the most suitable and ethical preventive measures. To effectively implement thalassemia prevention policies, a collaborative approach across multiple sectors is essential, aligning with national religious and health frameworks. The Ministry of Religious Affairs is crucial in this process, as it oversees marriage registration and premarital counseling. By incorporating thalassemia screening into Ministry of Religious Affair's existing processes, we can expand coverage and ensure that screening is both socially and religiously acceptable, turning prevention into a meaningful aspect of religious preparation for marriage.

Furthermore, the financial sustainability of preventive programs depends on strategic collaboration with BPJS Kesehatan, Indonesia's national health insurance agency. Instead of merely providing funding, BPJS should adopt a cost-sharing or front-loaded preventive investment model, where early screening costs are partly financed through existing preventive allocations. This approach promotes long-term fiscal sustainability by reducing the heavy curative burden from lifelong transfusions and chelation therapy. Investing early in prevention aligns with Indonesia's ongoing health financing reforms that emphasize value-based healthcare and efficiency in resource use.

Due to limited funding and lack of advanced medical equipment, Indonesia currently lacks definitive therapies such as genetic engineering and organ transplantation. Therefore, prioritizing community-based screening programs, including adolescent school screening and mandatory premarital tests, is crucial. National regulations should support the implementation of these programs to reduce the number of babies born with thalassemia major and allow the government to allocate more resources toward improving patients' quality of life.

Screening adolescents, particularly middle and high school students, is an organized and cost-effective approach (Chen et al., 2024). This age group is ideal because they have not yet entered the reproductive phase, providing opportunities for early education and genetic counseling (Miri-Moghaddam et al., 2014). Early screening initiatives have already been adopted in several countries, including Sardinia (Cao et al., 2013), Thailand (Wongprachum et al., 2016). India, England, Canada, Maldives (Cousens et al., 2010) and Egypt (Hesham et al., 2018), showing that sustained school-based screening remains one of the most practical and ethical strategies for countries with similar social and religious contexts.

IMPLICATIONS AND RECOMMENDATIONS

Lack of mandatory premarital screening for thalassemia in Indonesia has led to a rising number of newborns affected by the disease each year. To address this issue, health workers play a critical role in educating the public and promoting premarital screening for engaged couples. Given Indonesia's limited funding, medical infrastructure, and sociocultural sensitivities, thorough preventive screening is the most appropriate and cost-effective strategy.

For the Central Government

1. Establish a national regulation on thalassemia screening, either through a Minister of Health Regulation (Permenkes) or a joint regulation with the Ministry of Religious Affairs, mandating initial hematology examinations for engaged couples as part of mandatory health check-ups before marriage registration.

2. Define institutional roles and responsibilities:
   - The Ministry of Health oversees policy, screening protocols, and quality assurance.
   - The Ministry of Religious Affairs ensures screening integration within premarital counseling and marriage registration systems.
   - BPJS Kesehatan supports preventive financing through a cost-sharing or front-loaded scheme under JKN benefits.
   - Local health offices (Dinas Kesehatan) coordinate service delivery, data reporting, and follow-up counseling.

3. Standardize screening procedures, indicators, and educational materials, ensuring interoperability between the Information System of the Office of Religious Affairs (KUA) and Health Centers (Puskesmas).

4. Implement a pilot phase in three high-prevalence provinces (e.g., West Java, Central Java, and East Java) within the first 12 months, followed by national scale-up after evaluation.

5. Provide sustainable funding for preventive measures through JKN's promotive–preventive benefit scheme, covering school-based and premarital screening in regions with high thalassemia prevalence.

Basic Success Indicators

The success of the thalassemia prevention program can be measured with the following operational indicators:

1. Screening coverage rate: ≥70% of the target population in pilot provinces by Year 1 and ≥90% nationally by Year 3.
2. Reporting turnaround time: ≤7 days for local verification and ≤14 days for national data entry.
3. Counseling linkage rate: ≥80% of identified carriers receive counseling within 30 days.
4. Integration rate: ≥85% of screening data integrated into the National Health Information System (*SatuSehat*) and linked with the Ministry of Religious Affairs registry within the first 2 years.

These indicators will guide monitoring and evaluation during pilot implementation and nationwide scale-up, ensuring measurable progress toward sustainable thalassemia prevention.

For Local Governments

1. Enact regional regulations mandate adolescent screening in schools and premarital screening for couples, in alignment with national policy.
2. Strengthen referral and service networks between primary health centers (Puskesmas), hospitals, and genetic counseling units to ensure continuity of care and data flow.

3. Integrate national data across all stages, from registration and monitoring to evaluation and reporting, using a shared digital platform between Ministry of Health, Ministry of Religious Affairs, and local health offices.

Cross-Sectoral Public Awareness Recommendation

Launch a comprehensive national anti-stigma campaign in collaboration with the Ministry of Health, Ministry of Religious Affairs, BPJS Kesehatan, and community and religious leaders. The campaign should aim to normalize thalassemia carrier status as a common medical condition rather than a moral or social stigma.

Leveraging mass media, schools, and religious institutions, the initiative should spread accurate information about genetic inheritance and screening benefits, thereby reducing discrimination and increasing participation in screening. By framing carrier status as a neutral and manageable health condition, the campaign will help increase screening uptake, foster family and community acceptance, and strengthen the long-term social sustainability of thalassemia prevention programs.

Table 2. Implementation Timeline

Phase	Timeframe	Key Milestones
Phase 1: Pilot Implementation	Months 0–12	Screening launched in 3 high-prevalence provinces (West Java, Central Java, East Java). Target: ≥70% coverage, turnaround ≤14 days, ≥80% counseling linkage.
Phase 2: Evaluation & Scale-up Preparation	Months 13–18	Evaluation of system performance, refinement of indicators, nationwide training of health workers and religious counselors.
Phase 3: National Rollout	Months 19–36	Implementation across all provinces with national integration of screening and premarital data. Target: ≥90% national coverage and ≥95% data integration.

CONCLUSIONS

Approximately 6–10% of the Indonesian population carries the thalassemia gene, leading to the birth of about 2,500 babies with thalassemia major annually. Without effective prevention, this number could rise to tens of thousands, placing a significant strain on the national health budget due to the high cost of lifelong treatments such as blood transfusions and iron chelation therapy, reaching hundreds of millions of rupiah per patient. This burden also extends to families and caregivers, affecting their emotional well-being and economic productivity.

The Ministry of Health, together with patient foundations and local governments, has initiated preventive measures including school-based screening, premarital testing, and public awareness campaigns. While these programs have improved carrier detection and public knowledge, their coverage remains limited due to cultural and religious sensitivities, social stigma, and uneven funding.

Establishing standardized, affordable, and culturally acceptable screening and counseling processes will significantly reduce the number of children born with thalassemia major. Integrating prevention within the national health insurance (JKN) framework, enhancing data systems, and ensuring sustainable financing mechanisms are critical to strengthening Indonesia's thalassemia prevention strategy.

These policy reforms can foster comprehensive, inclusive, and sustainable preventive measures, supported by clear institutional collaboration between the Ministry of Health, Ministry of Religious Affairs, BPJS Kesehatan, and local governments. Ultimately, thalassemia screening should not be perceived as a financial burden but a value-based public health investment that ensures long-term savings, health equity, and system efficiency. Lending Indonesian contexts, this policy brief offers a valuable lesson for other developing countries struggling to implement national health insurance systems. It demonstrates the importance of integrating primary prevention into health financing schemes from the outset to achieve sustainability, social acceptance, and long-term fiscal resilience.

DECLARATION

Ethics approval and consent to participate

Ethical approval and informed consent were not required for this study because it is a policy analysis based exclusively on publicly available literature, policy documents, regulations, and secondary sources. The study did not involve human participants, identifiable personal information, biological specimens, or the collection of primary data.

Consent for publication

Not applicable. This article does not contain any individual person's identifiable data, images, or other personal information requiring consent for publication.

Availability of data and materials

No new datasets were generated or analyzed during this study. All information used in this policy analysis was obtained from publicly available literature, official government documents, regulations, reports, and other sources cited in the article.

Conflicts of Interest Statement

The authors declare that they have no competing or conflicting interests that could have influenced the preparation, interpretation, or conclusions of this policy analysis.

Statement on the Use of Artificial Intelligence (AI)

The authors declare that generative artificial intelligence (AI) tools were not used to generate scientific content, analyze data, interpret findings, or formulate the conclusions of this manuscript.

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Authors' Contributions

All authors have read and approved the final version of the policy brief. The first author was responsible for conceptualizing the topic, collecting and synthesizing evidence, and drafting the initial version of the policy brief. The second and third authors provided guidance on structure, critically reviewed the content, refined the arguments, and performed final editing. All authors have read and approved the final version of the policy brief.

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