

# Families' hopes for strengthening education to bridge thalassemia knowledge gap: a phenomenological study

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## Abstract

The prevention of thalassemia, particularly through early detection, is a significant concern that is currently inadequately addressed in Indonesia, where the condition is not widely comprehended. To develop effective family- and community-based health promotions and interventions, it is crucial to consider the perceptions and hopes that patients' family members have about thalassemia education. This qualitative study employed a phenomenological approach, involving 24 family members of thalassemia patients from the Java and Sumatra Islands, to investigate their perspectives and hopes for strengthening thalassemia prevention strategies. Four themes emerged from analyzing the interview transcript data using the Collaizi method: i) the importance of early premarital education; ii) the hope that thalassemia will be included in the school curriculum; iii) the necessity to broaden thalassemia education across various facilities; and iv) the engagement of other sectors in thalassemia screening and prevention.

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Key words: education; family; prevention; screening; thalassemia.

Contributions: FIH, MNMD, KM, AAW, TTT, manuscript writing and data analysis; FIH, DR, data collection. All the authors have read and approved the final version of the manuscript and agreed to be accountable for all aspects of the work.

Conflict of interest: the authors declare no potential conflict of interest.

Ethics approval and consent to participate: not required.

Funding: this study was financially supported by a research team.

Acknowledgments: the authors would like to express their deepest gratitude to all parties, including POPTI Indonesia, for their valuable contributions to this study.

Received: 17 December 2024

Accepted: 26 March 2025

Early view: 13 June 2025

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Healthcare in Low-resource Settings 2025; 12(s2):13493

doi:10.4081/hls.2025.13493

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This study highlights the necessity for the government to provide adequate support for thalassemia prevention. To enhance the effectiveness of thalassemia prevention, the government and other relevant parties should promptly develop prevention programs at the school level and implement premarital screening regulations in marriage institutions.

## Introduction

Thalassemia is one of the most common hereditary blood disorders in Indonesia and can manifest in a wide range of severities throughout the country. Based on the assumption that 5% of the population is affected by this condition, approximately 2,500 new major cases are anticipated annually.<sup>1,2</sup> The management of thalassemia in Indonesia is centered on supportive measures, such as blood transfusions, iron chelation, monitoring of complications, psychosocial support, and a seamless transition from pediatric to adult clinics.<sup>1,3</sup> One of the strategies used to prevent thalassemia is screening,<sup>4</sup> with carrier screening being the most extensively used genetic screening test in various nations.<sup>5</sup>

Several countries, including Thailand, Iran, Singapore, the United Kingdom, and Turkey, have implemented thalassemia screening procedures for the population.<sup>6-10</sup> This is considered one of the applicable solutions for preventing thalassemia in Pakistan.<sup>11</sup> In contrast, 95.7% of Indonesian adolescents did not participate in thalassemia screening despite knowing that thalassemia is an illness associated with an abnormality of red blood cells and that screening for this condition is essential.<sup>12</sup> Another study in Indonesia revealed that 75.4% of premarital individuals were unaware of thalassemia.<sup>13</sup> A similar situation was observed in Oman.<sup>14</sup> Meanwhile, in Bangladesh, 89.3% of adults were aware of premarital carrier screening, whereas 30.5% were reluctant to undergo the test; undergraduate students' and parents' knowledge and awareness of premarital screening for  $\beta$ -thalassemia were insufficient in this country.<sup>15-17</sup>

Despite the importance of early diagnosis and optimal therapeutic interventions for improving patient outcomes and quality of life,<sup>15,18,19</sup> information regarding thalassemia screening and prevention remains extremely limited in Indonesia. Previous studies indicate that Indonesian youth generally exhibit poor knowledge and practices regarding thalassemia.<sup>20,21</sup> A preliminary study, based on interviews with a principal administrator of the Association of Parents of Thalassemia Patients Indonesia (*Persatuan Orang Tua Penderita Thalassemia Indonesia* [POPTI]), indicates that family members caring for thalassemia patients may possess the sole understanding of this condition, as they obtain information directly from physicians. However, because they are not health professionals, they are often not trusted when sharing information with other family members. One family member claimed that they had never heard of screening and

assumed that thalassemia was a condition related to anemia. This indicates a knowledge gap regarding thalassemia among family members. If families, as key players in prevention, continue to hold misconceptions about thalassemia and its screening initiatives, reaching a broader population will be more challenging.

Addressing this knowledge gap requires prioritizing family- and community-based health education. Family members are crucial in disseminating health information and supporting prevention efforts; therefore, understanding their perceptions and expectations regarding thalassemia education is essential. If misconceptions persist within families, promoting screening and prevention at the community level will be challenging. This study aimed to explore the hopes and perspectives of thalassemia patients' family members in strengthening educational initiatives. By capturing their insights, this study seeks to inform effective strategies and interventions that empower families and communities to bridge the knowledge gap and foster a proactive approach to thalassemia prevention in Indonesia.

## Materials and Methods

### Study design

This study employed a qualitative research design, using a phenomenological approach. The phenomenological method was chosen to explore the perceptions and expectations of family members of thalassemia patients regarding thalassemia education. This approach allows for an in-depth understanding of how families interpret existing educational initiatives and their hopes to strengthen thalassemia awareness and prevention efforts.

### Participants

This study involved 24 family members of thalassemia patients who were active members of the POPTI from the Java and Sumatra regions, aged over 18 years, and had experience as caregivers of thalassemia patients. The participants were selected using a purposive sampling technique. Following the determination of sample size based on data saturation in qualitative research, interviews were conducted until no new themes emerged from data analysis.

### Variables and instruments

The perspectives and hopes of family members investigated in this study are those directed toward the government, community, and health professionals regarding premarital thalassemia screening and education to bridge the thalassemia information gap using their experiences. The instruments utilized in this study included a sound-recording device for offline interviews and a Zoom meeting application for online interviews.

### Data collection

Considering the researchers' experience and the vast geographic scope of the studied areas, data were gathered through both offline and online in-depth interviews conducted between September 2023 and February 2024 in Java and the Sumatra Islands, using open-ended questions. Each interview session lasted 45-90 minutes. Interviews were carried out face-to-face with two participants from Java Island and online with 22 other participants via Zoom meetings at predetermined times. All the interview data were recorded and transcribed *verbatim*.

### Data analysis

The Collaizi technique was used to analyze the interview tran-

scripts with Open Code Software 4.03 Umea, which was utilized to generate codes, categories, and themes. The Indonesian themes were translated into English and reviewed by a research team comprising experts in family medicine and health promotion from the Malaysia Sabah University.

### Validity and reliability

Source triangulation with other family members was used to ensure the validity and reliability of information. Data analysis involved peer debriefing with two thalassemia specialist nurses from Indonesia. During the peer debriefing process, emerging topics were thoroughly discussed to acquire a better understanding of participants' experiences.

### Ethical clearance

The research ethics review was carried out following the WHO CIOMS guidelines and approved with No. E5a/126/KEPUMM/IV/2023 by the Ethics Committee of Muhammadiyah Malang University.

## Results

### Characteristics of participants

The results showed that the participants were predominantly women (70.83%) who received secondary education (58.33%) and primarily worked in the informal sector (37.50%). Most of them earned  $\leq 3,842,000$  rupiahs per month (79.17%) and lived in Java regions (79.17%) with a distance to health facilities of 1-25 km (50%). The majority of participants were members of the patients' nuclear family (95.83%) and already had health insurance (83.33%). However, despite having relatively easy access to health facilities, only 29.17% had undergone a thalassemia screening test, indicating low participation in screening.

### Thematic findings

Based on the results of the in-depth interviews with participants, the findings of this study can be classified into four themes: i) the importance of premarital education at an early age; ii) the hope that thalassemia will be included in the school curriculum; iii) the need to expand thalassemia education across numerous facilities; and iv) the involvement of other sectors in thalassemia screening and prevention.

### Theme 1. The importance of premarital education at an early age

#### Premarital education at school age

The participants emphasized the need for premarital education. To prevent the late diagnosis of thalassemia, they hope that thalassemia screening education before marriage is implemented as early as possible, preferably during school age, such as in junior or senior high school, vocational school, or university/college years.

"As for premarital education, yes, that's when children reach prepubescent age, and it must start at prepubescent age, right, when they begin to understand how they like others." (P10)

This is supported by P12, who stated, "From vocational school, I think. The first year of vocational school, in my opinion, is [the right time for thalassemia] education."

### *Thalassemia education as an early parenting topic*

In reference to other families with thalassemia, participants hope that parents will educate their children about thalassemia before marriage, so that they can recognize the symptoms as early as possible.

“So, [the same incident as] my little brother or child [or] my older brother [will not happen again]. Yes, XXX said earlier, to look for a partner in the future. I gave him early notice, Ma’am. Because he is already in the third year of vocational school, he can understand [easily].” (P16)

## **Theme 2. The hope that thalassemia will be included in the school curriculum**

### *Limited resources and materials on thalassemia at school*

Currently, there is a lack of educational materials available in schools on thalassemia and other teen-related health topics, such as anemia and drugs. Participants hope that this limited knowledge of thalassemia will be addressed soon so that greater awareness about this condition can be raised among the extended family, and the symptoms can be detected when they occur in other family members. This is stated by participants with school-age children and/or siblings.

“If, for example, it is stated in the school textbook what thalassemia is, they can find out.” (P15)

### *Hope for extensive literature on thalassemia*

This involves providing information about thalassemia in educational subjects for students.

“At school, we have the habit of reading literature. So, usually, we are also asked to look for information. (Maybe) we can also look up thalassemia online every Thursday.” (P11)

## **Theme 3. The need to expand thalassemia education across numerous facilities**

### *Hope for better thalassemia education from community health centers and media outlets*

Various institutions in Indonesia can contribute significantly to the provision of thalassemia education, including the Integrated Health Post (*Pos Pelayanan Terpadu/Posyandu*), Community Health Centers (*Pusat Kesehatan Masyarakat/Puskesmas*), government agencies at the village or sub-district level, Family Welfare and Empowerment organizations (*Pemberdayaan dan Kesejahteraan Keluarga* [PKK]), and social forums such as community gatherings. The participants highlighted the poor functioning of these institutions in thalassemia education.

“So, what, they [the health workers] are the only ones present in Puskesmas. So, the only chance is to give what it is... patient referral (just like that). There is nothing more. No [proper education]. So, what should I do? How... I am also [very] confused.” (P16)

### *Hope for thalassemia education through social media platforms*

In addition to the various institutions, participants also hope that thalassemia education will utilize attractive methods, such as social media platforms, media production, banners at health centers, and educational models in the form of videos. The use of various types of information media, including social media, must be developed.

“Posyandu, Puskesmas, I don’t think many people still under-

stand, Instagram, TikTok... those are needed too, you know.” (P2)

This statement is emphasized by P12, who stated, “Yes, I hope so, Ma’am. [I hope] the community or the government pays more attention to children with thalassemia.”

## **Theme 4. The involvement of other sectors in thalassemia screening and prevention**

### *Hope for enhancing the role of marriage institutions in premarital thalassemia screening programs*

The Office of Religious Affairs (*Kantor Urusan Agama* [KUA]) is a marital institution in Indonesia that provides premarital education to all married citizens. Participants hope that KUA will be the first institution to screen couples for thalassemia prior to their marriage.

“The best thing (for thalassemia screening education) is to go to KUA. Go to KUA first.” (P3)

### *Hope for the development of a premarital screening policy by the government*

According to participants, state-owned marriage institutions should make premarital thalassemia screening mandatory, prohibit marriage for groups at risk of having thalassemia, or guide prospective brides and grooms about planning for children after marriage, particularly if they or their partners are at risk of having thalassemia.

“Next, inputs from community health centers were used to establish the database at the health office. Other inputs are provided by regional hospitals that have the necessary equipment or labs. [All of these inputs] will reach all related offices. Where is the output? It goes to the KUA, churches, or temples that handle wedding ceremonies. There, you can access it using a certain password. Click on XXX’s name and enter the National Identity Number (Nomor Induk Kependudukan/NIK). Simply click there. Have you yet been screened? If not, sorry, you’re not allowed... pause [the process]. You [need to undergo] screening first. If you have been screened and it turns out that you are a carrier, stop [the process]. You must first consult the marriage counselor. Okay, that’s it. Therefore, this is not reckless. [The government] should prepare marriage counselors.” (P1)

## **Discussion**

### **Improving early access to premarital thalassemia education**

This study highlights the importance of providing thalassemia education as early as possible to enhance the understanding of the disease and increase awareness of its signs, thereby encouraging early screening and prevention. This aligns with previous studies indicating that education for adolescents improves knowledge, attitudes, and awareness regarding thalassemia and its prevention.<sup>22-24</sup> According to data from the 2019 to 2022 National Socio-Economic Survey, the average age at first marriage in Indonesia was 21.23 years in 2023. Individuals in this early adulthood often focus on various life events such as completing their education, getting married, having children, and building a career. However, the utilization of premarital screening in Indonesia remains low.<sup>25</sup> In Turkey, mandatory premarital screening has led to the cancellation of 53% of at-risk marriages and an 80% reduction in at-risk

births. Similar programs have significantly reduced the prevalence of thalassemia in Arab countries, including Bahrain.<sup>26</sup> Parents of children with thalassemia recommend that premarital screening be conducted during junior or senior high school (ages 13-20 years), as this period marks the transition from adolescence to early adulthood. In Malaysia, screening is considered suitable for students aged 16-17.<sup>27</sup> Therefore, thalassemia education should be provided to adolescents, and the government should consider implementing policies to integrate thalassemia education into the school curriculum. Raising awareness among adolescents will facilitate early detection of thalassemia and contribute to its prevention.

### Enhancing school-based thalassemia education and prevention programs

The findings suggest that education about thalassemia should be incorporated into the school curriculum. Adolescence is a crucial period for acquiring knowledge about thalassemia, as it can foster awareness and encourage preventive measures. Studies have shown that adolescent brain development involves cognitive changes that enable the processing of new and complex information, as well as improvements in social functioning.<sup>28</sup> This makes adolescence an optimal stage for understanding important health-related topics, including thalassemia. In Indonesia, school-based education on thalassemia information and prevention has not been widely explored. The School Health Unit (*Usaha Kesehatan Sekolah* [UKS]) provides essential health education.<sup>29-31</sup> However, it does not specifically address thalassemia. In contrast, school-based education programs in other countries have been shown to positively impact various health domains, including oral health, nutrition, asthma management, and cancer awareness (breast and lung cancer).<sup>32-35</sup> The findings reveal that thalassemia-related materials should be incorporated into the school curriculum. However, the number of participants screened was low. This suggests that the presence of thalassemia cases among family members does not significantly influence willingness to screen, highlighting a challenge in prevention. Data on premarital screening, especially among extended families, remains insufficient and requires further investigation. This study underscores the importance of integrating thalassemia education into school curricula to enhance adolescent awareness and prevention efforts. Low screening uptake remains a significant challenge, necessitating stronger premarital screening initiatives and further research on family participation in preventive strategies.

### Expanding thalassemia education through various social media platforms

These findings highlight that long distances can limit access to instructional materials from hospitals. Therefore, online resources may serve as ideal alternatives, as they are not constrained by time or location. Diverse media, including social media, should support education about thalassemia. Indonesia has one of the highest numbers of social media users, and in recent years, social media has become a powerful marketing tool for Indonesian businesses.<sup>36</sup> Given this trend, both public and healthcare workers can effectively use social media to raise awareness about thalassemia. Indonesia's vast geography has resulted in numerous administrative and political entities, including those in the health sector. Puskesmas operates at the sub-district level, while Posyandu functions at the village level, enabling direct outreach to residents based on proximity. Furthermore, the PKK may serve as an effective platform for delivering thalassemia education at the grassroots level. This approach aligns with previous studies showing the pos-

itive impact of community-based infant nutrition programs on health education among rural women and supports recommendations on community empowerment,<sup>37</sup> which suggest that adaptive health interventions should be tailored to local contexts. Prior research has emphasized the crucial role of community development in fostering sustainable organizations.<sup>38</sup> Online resources and social media enhance thalassemia education by overcoming geographical barriers. Community-based health structures, such as *Puskesmas*, *Posyandu*, and *PKK*, provide localized education opportunities, aligning with empowerment strategies for sustainable health awareness and intervention.

### Enhancing the role of marriage institutions for thalassemia screening

The findings strongly support the integration of premarital thalassemia screening into Indonesia's marriage institutions, particularly through the KUA. Participants advocated mandatory screening policies to identify at-risk couples, prevent transmission, provide informed reproductive counseling, and prevent them from having children with thalassemia. Premarital screening is an essential solution to prevent the occurrence of thalassemia. This corresponds with other research indicating that premarital screening is mandatory in Turkey, Palestine, and Iran, whereas Italy, the Maldives, Greece, and Canada have voluntary screening programs.<sup>5</sup> This has contributed to a reduction in thalassemia by identifying carriers and at-risk couples, thereby informing reproductive choices.<sup>39</sup> However, thalassemia education and training for educators and marriage counselors should be prepared in advance. To design the flow, guidelines, and technical implementation of thalassemia screening, as well as screening for other disorders before marriage, cross-sector coordination between the government and marriage institutions is necessary. Continuous efforts in education and counseling are crucial to further reduce the burden of thalassemia.

## Conclusions

This study identified four key themes regarding thalassemia patients' family members' hopes for education and prevention: i) premarital education at an early age; ii) inclusion in the school curriculum; iii) expanding education across numerous facilities; and iv) involving other sectors in screening and prevention. This challenges hospitals and health professionals to improve community health promotion programs. The expectations pose a challenge to initiating cross-sector collaboration aimed at preventing thalassemia from spreading in Indonesia and achieving the country's vision of zero-born thalassemia. The Ministry of Education, educational institutions, and local governments should integrate thalassemia education into the school curriculum. Furthermore, the Indonesian government is expected to develop guidelines and tools for screening in marriage institutions. Hospitals, health offices, and health insurance companies must assess whether screening at marriage institutions will lead to further testing of individuals at risk of thalassemia.

## References

1. Wahidiyat PA, Sari TT, Rahmartani LD, et al. An insight into Indonesian current thalassaemia care and challenges. *ISBT Sci Ser* 2020;15:334-41.

2. Rahmayani S, Cahyadi A, Andarsini MR, et al. Blood transfusion compliance in children with transfusion-dependent Thalassemia. *Edelweiss Appl Sci Technol* 2025;9:856-66.
3. Qatrunnada H, Bintoro SUY, Wahyuni S. Drug utilization study and cost analysis of adult  $\beta$ -thalassemia major patient therapy at Dr. Soetomo General Hospital Surabaya. *J Basic Clin Physiol Pharmacol* 2021;32:611-6.
4. Old J, Angastiniotis M, Eleftheriou A, et al. Prevention of Thalassaemias and Other Haemoglobin Disorders, 2nd edition. *Prevention of Thalassaemias and Other Haemoglobin Disorders: Volume 1: Principles*. Thalassemia International Federation; 2013.
5. Cousens NE, Gaff CL, Metcalfe SA, Delatycki MB. Carrier screening for Beta-thalassaemia: A review of international practice. Vol. 18, *European Journal of Human Genetics*. Nature Publishing Group; 2010, p. 1077-83.
6. Hosoya S. Changes in attitudes towards marriage and reproduction among people with a genetic illness: A study of patients with Thalassemia in Iran. *Anthropol Middle East* 2017;12:28-45.
7. Verdonk P, Metselaar S, Storms O, Bartels E. Reproductive choices: a qualitative study of Dutch Moroccan and Turkish consanguineously married women's perspectives on pre-conception carrier screening. 2018 [cited 2023 Aug 10]; Available from: <https://doi.org/10.1186/s12905-018-0574-4>
8. Xu JZ, Foe M, Tanongsaksakul W, Suksangpleng T, Ekwattanakit S, Riolueang S, et al. Identification of optimal thalassemia screening strategies for migrant populations in Thailand using a qualitative approach. *BMC Womens Health* 2018;18:79.
9. Dheensa S, Metcalfe PA, Williams R. What do men want from antenatal screening? Findings from an interview study in England. *Midwifery* 2015;31:208-14.
10. Lee SY, Yap ES, Lee EY, Goh JH, Liu TC, Yip C. Evaluation of Thalassaemia Screening Tests in the Antenatal and Non-Antenatal Populations in Singapore. *Ann Acad Med Singap* 2019;48:5-15.
11. Ahmed S, Jafri H, Faran M, et al. Cascade screening for beta-thalassaemia in Pakistan: relatives' experiences of a decision support intervention in routine practice. *Eur J Hum Genet* 2022;30:406-12.
12. Wahidiyat PA, Yo EC, Wildani MM, et al. Cross-sectional study on knowledge, attitude and practice towards thalassaemia among Indonesian youth. *BMJ Open* 2021;11.
13. Utami ST, Kusumaningrum NSD. Knowledge of Premarital Couples Regarding Premarital Screening Thalassemia. *Jurnal Keperawatan* 2020;11:180-7.
14. Al-Farsi OA, Al-Farsi YM, Gupta I, Ouhtit A, Al-Farsi KS, Al-Adawi S. A study on knowledge, attitude, and practice towards premarital carrier screening among adults attending primary healthcare centers in a region in Oman. *BMC Public Health* 2014;14:380.
15. Ansharullah BA, Sutanto H, Romadhon PZ. Thalassemia and iron overload cardiomyopathy: Pathophysiological insights, clinical implications, and management strategies. *Curr Probl Cardiol* 2025;50:102911.
16. Pervin S, Sultana H, Ahmed T, et al. Knowledge and Awareness Regarding Premarital Screening of  $\beta$ -thalassemia among Undergraduate Students in Bangladesh. *J Current Med Res Opinion* 2021;4:730-7.
17. Hossain MS, Mahbub Hasan M, Petrou M, et al. The parental perspective of thalassaemia in Bangladesh: lack of knowledge, regret, and barriers. *Orphanet J Rare Dis* 2021;16:315.
18. Halim-Fikri H, Zulkipli NN, Alauddin H, et al. Global Globin Network and adopting genomic variant database requirements for thalassemia. *Database* 2024;2024.
19. D'Arqom A, G Putri M, Savitri Y, Rahul Alfaidam AM. Vitamin and mineral supplementation for  $\beta$ -thalassemia during COVID-19 pandemic. *Future Sci OA* 2020;6:FSO628.
20. Wahidiyat PA, Yo EC, Wildani MM, et al. Cross-sectional study on knowledge, attitude and practice towards thalassaemia among Indonesian youth. *BMJ Open* 2021;11.
21. D'Arqom A, Indiatuti DN, Nasution Z. Online peer-group activism for thalassemia health education during the COVID-19 pandemic: a case study from East Java, Indonesia. *J Health Res* 2022;36:158-65.
22. Tan HY, Hussein N, Lee YK, Abdul Malik TF. Adolescents' experiences and views of the national school-based thalassaemia screening programme in Malaysia: a qualitative study. *J Community Genet* 2023;14:361-9.
23. Miri-Moghaddam E, Motaharitarab E, Erfannia L, et al. High school knowledge and attitudes towards Thalassemia in south-eastern Iran. *Int J Hematol Oncol Stem Cell Res* 2014;8:24-30.
24. Triatin RD, Rakhmilia LE, Sribudiani Y, Susanah S. Knowledge towards Thalassemia and Willingness to Screen among Students in Public Senior High School 3 Bandung. *Althea Med J* 2022;9:241-7.
25. Rujito L, Pusparini I, Lestari DWD, Mulyanto J. Educational intervention to improve knowledge and attitudes about thalassemia premarital screening surveys among Muslim societies: a pilot study in Indonesia. *Jurnal Keperawatan Soedirman* 2023;18:30-6.
26. Al-Balushi AA, Al-Hinai B. Should premarital screening for blood disorders be an obligatory measure in Oman? *Sultan Qaboos Univ Med J* 2018;18:e24-9.
27. Tan HY, Hussein N, Lee YK, Abdul Malik TF. Adolescents' experiences and views of the national school-based thalassaemia screening programme in Malaysia: a qualitative study. *J Community Genet* 2023;14:361-9.
28. Committee on the Neurobiological and Socio-behavioral Science of Adolescent Development and Its Applications. *The Promise of Adolescence: Realizing Opportunity for All Youth* [Internet]. Bonnie RJ, Backes EP, editors. Washington, D.C.: National Academies Press; 2019. Available from: <https://www.nap.edu/catalog/25388>
29. Nugraheni H, Sukini, Prayoga AN. Survey of satisfaction on school health unit service at elementary school. *Indian J Public Health Res Dev* 2019;10:815-20.
30. Nafiisah M, Sulistyorini Y, Indriani D, et al. analysis of UKS management readiness and my health report books in elementary school of Surabaya City and Gresik District. *Jurnal Biometrika dan Kependudukan* 2022;11:72-9.
31. Soenarnatalina M, Sulistyorini Y, Indriani D. The importance of student health record books in school to realize children's health. *Opcion* 2019;35:2899-921.
32. Geetha Priya PR, Asokan S, Janani RG, Kandaswamy D. Effectiveness of school dental health education on the oral health status and knowledge of children: A systematic review. *Indian J Dent Res* 2019;30:437-49.
33. Hamulka J, Wadolowska L, Hoffmann M, et al. Effect of an education program on nutrition knowledge, attitudes toward nutrition, diet quality, lifestyle, and body composition in polish teenagers. *The ABC of healthy eating project: Design, protocol, and methodology*. *Nutrients* 2018;10.
34. Culmer N, Smith T, Stager C, et al. Telemedical Asthma Education and Health Care Outcomes for School-Age

- Children: A Systematic Review. *J Allergy Clin Immunol Pract* 2020;8:1908-18.
35. Williams LB, McCall A, Joshua TV, et al. Design of a Community-Based Lung Cancer Education, Prevention, and Screening Program. *West J Nurs Res* 2019;41:1152-69.
36. Social media in Indonesia - statistics & facts | Statista [Internet] [cited 2024 Dec 16]. Available from: <https://www.statista.com/topics/8306/social-media-in-indonesia/#topicOverview>
37. Mapesa J, Meme J, Muthamia O. Effect of community-based nutrition on infant nutrition and associated health practices in Narok, Kenya. *Afr Health Sci* 2020;20:724-34.
38. Giebel C, Shrestha N, Reilly S, et al. Community-based mental health and well-being interventions for older adults in low- and middle-income countries: a systematic review and meta-analysis. *BMC Geriatr* 2022;22.
39. Karakaya T, Silan F, Ozdemir O. A New Mutation, Hb A2-Canakkale [ $\delta 10(A7)Ala \rightarrow Val$ ; HBD: c.32C>T], and Other Well-Known  $\delta$  Variants Identified in a Selected Cohort with Low Hb A2 Levels. *Hemoglobin* 2022;46:87-90.