

## Congenital heart disease screening program in elementary schools: a research-based policy

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### Abstract

**Purpose:** CHD is a condition where heart abnormalities develop before birth and can lead to severe complications such as heart failure and premature death, especially among younger adults. Delayed diagnosis and treatment worsen the situation for CHD patients. Early screening can prevent CHD and ensure timely interventions. This study discusses the latest advancements in CHD screening for primary school children and the valuable insights gained from the program. **Method:** The CHD screening program in Yogyakarta province involved three stages: consolidation, implementation, and incorporation. During the consolidation stage, key decision-makers in the province and local health offices were involved. Primary healthcare workers and primary school teachers were trained to deliver the screening during the implementation stage. Stakeholders, health workers, and teachers were invited to discuss the results, and the Provincial Governor's office was engaged during the incorporation stage. **Results:** In 2018–2019, 18 CHDs were identified from 6,116 school-age children in 4 districts in Indonesia. The screening program was led by academics in the Universitas Gadjah Mada through 3 stages: consolidation, implementation, and incorporation. Strong collaboration with local stakeholders has contributed to the program's success in engaging 130 schools, 60 community health centers, and 190 health workers. Several opportunities for improvement are: strengthening the capacity and number of health providers at health centers to screen CHDs using 12-lead electrocardiography, addressing patients' reluctance to visit the health facility due to the COVID-19 pandemic, and motivating parents to have their children checked. **Conclusion:** CHD screening using 12-lead electrocardiography and auscultation should be part of primary school health screenings. Academics can train health workers, and local governments can provide funding and prepare health facilities for follow-up treatment.

**Keywords:** cervical cancer; level of knowledge; counseling; CHD screening; school health program

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## INTRODUCTION

Congenital Heart Disease (CHD) refers to a heart defect caused by heart development abnormality during embryogenesis, which is one of the primary causes of death in the first year of life, and some cases are associated with genetic defects [1]. In 2017, CHDs were responsible for over 250,000 deaths globally, with higher mortality and morbidity rates observed in countries with lower income and higher fertility rates, including the Southeast Asia region [2]. Given Indonesia's large population and high fertility rate, the country is likely to have a substantial burden of CHD cases. However, national data on CHDs is limited. According to the Indonesian Ministry of Health, the prevalence of CHD was 10 per 1,000 live births [3].

Prevention and management of birth defects in Indonesia have become one of the priorities in maternal, neonatal, and child health (MNCH) recently, and screening of neonates using pulse oximetry is included as mandatory screenings before discharge after birth [3]. Most children born with atrial septal defect (ASD), one of the most common CHDs, have mild symptoms or are asymptomatic, thus undiagnosed until adulthood [4]. From 2012 to 2017, there were 1012 adults with CHDs, indicating that neonatal screening may have missed a significant number of cases. A study showed that out of 838 children aged <18 with CHDs, 23% were diagnosed after 5 years old [6]. Without early treatment, CHDs could cause excess lung circulation and increased right heart volume load, leading to pulmonary arterial hypertension (PAH). The delayed diagnosis and treatment cause major health and economic problems since PAH treatment is costly and decreases patients' quality of life and productivity [2, 7].

Studies in Egypt, India, and Nigeria identified CHD prevalence of 1.0, 10.4, and 6.6 per 1000, respectively, by examining clinical signs and performing echocardiography simultaneously [8-10]. A study in rural China, using the same method as the other studies, managed to detect 285 cases of CHDs in 21,861 school-age children, thus demonstrating a prevalence of 13.0 per 1000 [11]. A recent study in 6,116 primary school children in Indonesia, using the 2-step clinical screening using electrocardiography and auscultation followed by confirmation using echocardiography, identified a CHD prevalence of 2.9 per 1000. This offers a more efficient approach to detecting CHDs in school-age children. Using the tiered early detection method, CHD can be detected early before more severe clinical manifestations appear, and corrective action can be performed [12].

Patients with CHD found in adulthood have shown symptoms and signs of complications. The most common is PAH, heart failure, and Eisenmenger syndrome [13]. Patients with CHD who experience this complication have high morbidity and mortality rates, and because most of them occur in young adults who are of productive age, their quality of life and productivity will decrease [5]. In addition, the government's cost burden for CHD management is also high due to the long-term treatment and high medicines prices. Therefore, early case finding through screening allows CHDs to be completely corrected and requires a shorter-term and less expensive treatment. To reduce the prevalence of CHD in adulthood, preventive measures in the form of early detection of CHDs in childhood need to be carried out through a screening program that is simple, applicable, and acceptable by children, families and communities, and effective. A simple but thorough cardiac examination method can effectively identify children with CHDs that often present without typical symptoms and signs. These cases should have an early corrective treatment to prevent complications in adulthood [14].

Many CHDs in adulthood in Indonesia indicate a lack of detection for diagnosis in early childhood, even in infants. While the routine health screening program for school-age children has been rolled-out nationwide, it does not include screening for CHDs. This article describes the processes, facilitators, and barriers in initiating and implementing CHD screening in primary school-age children in Yogyakarta province, thus providing lessons learned for other districts or provinces in Indonesia and other regions in low- and middle-income nations.

## METHODS

*Study period.* This study had three stages. First, the consolidation stage (August 2015–May 2021), which was qualitative research by conducting focus group discussions, workshops, and in-depth interviews with health workers, the provincial health office, provincial education-youth-sports offices, and key stakeholders, followed by training for health workers to perform the screening.

Second, the implementation phase (April 2018 – ongoing), which was quantitative population research with a descriptive observational study method that examines primary school children in 2 stages: 1) primary screening: clinical examination using the 12-lead electrocardiography and auscultation at school, and 2) secondary screening: confirming the abnormal

findings using echocardiography at the referral facilities. As of 2022, this has recruited 7000 samples.

Third, the incorporation stage (July 2020 – ongoing), in which, on top of the existing stakeholders involved since the consolidation stage, stakeholders from the Provincial Government were engaged. Engaging the Provincial Government, particularly the Bureau of Law, Bureau of Research, and the Governor itself, allowed the researcher to advocate the development of laws and regulations for implementing CHD early detection programs for primary school children. At this stage, the research team also developed academic manuscripts, which served as the scientific justification for the laws and regulation development.

*Study population.* The screening program was conducted in 5 districts in Yogyakarta province: Yogyakarta municipal, Sleman, Bantul, Kulon Progo, and Gunung Kidul. The number of schools selected per district was based on 2017 data of total school students. Puskesmas selection was based on the performance, equipment, and recommendation by the District Health Offices that supervise each community healthcare facility (puskesmas).

## RESULTS

### ***Consolidation: stakeholder engagement***

For this CHD screening, collaborations with provincial and district governments were established. We worked with the Provincial and District/Municipal Health Offices, Provincial Education Youth & Sports Office, puskesmas, and primary schools. A total of 25 local stakeholders' representatives were interviewed, with four discussion sessions involving health workers at puskesmas and teaching staff at primary schools.

*Consolidation: Health worker training.* At least one general practitioner and one nurse from each puskesmas were invited to attend the training. In 2018 – 2019, there were 45 general practitioners and 45 nurses who received two times training for 6 hours each. Invited GPs and nurses were those specializing in managing school student health programs. The training topics covered: updated diagnosis and management of CHD, heart physical examination, ECG interpretation, and CHD screening procedures in students. A quiz is held to assess the improvement in participants' knowledge and skill after the training.

### ***Implementation: screening procedure***

To ensure that the integration of a new program into an existing routine is successful, it is important to

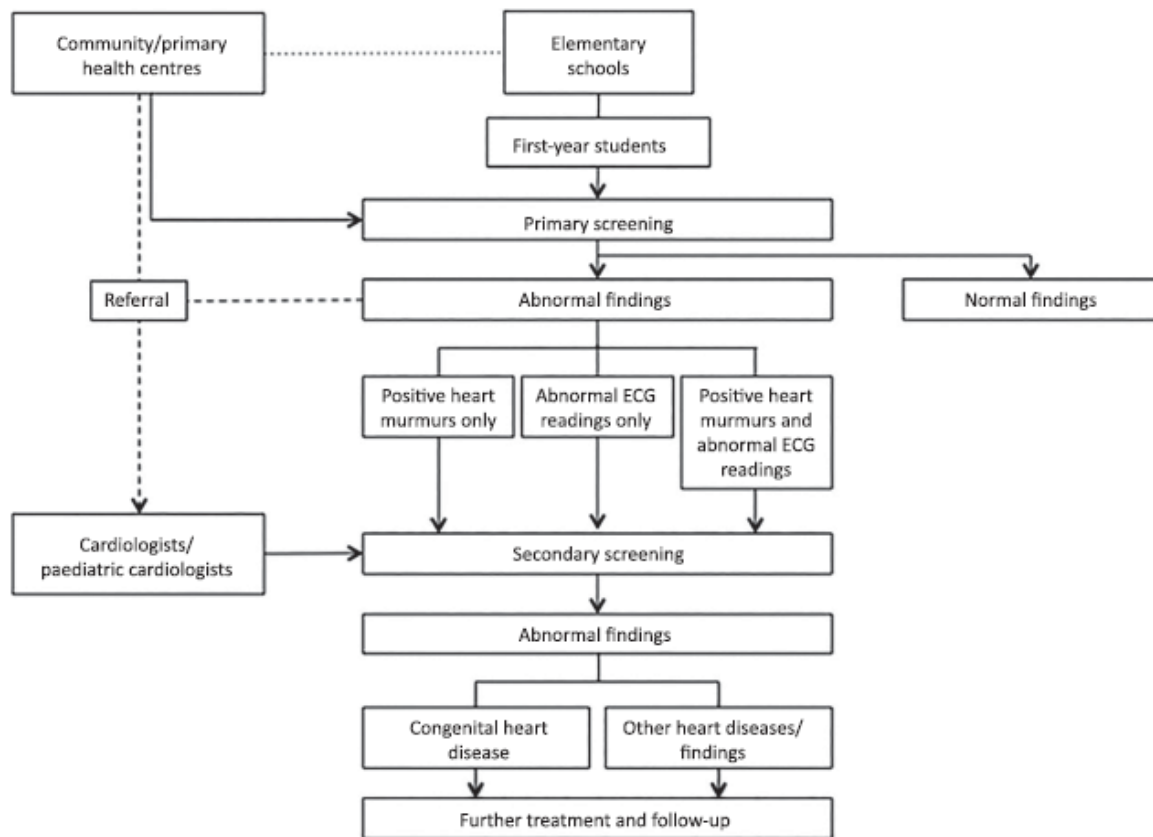
consider the roles and responsibilities of each stakeholders involved. In the case of the CHD screening program, the health personnel from the puskesmas and school teachers and volunteers played a critical role in conducting the routine health examinations and administering the CHD screening. By incorporating the CHD screening into the existing routine, the program was able to take advantage of the infrastructure and resources that were already in place. Additionally, the supervision provided by the research team members ensured that the screening program was implemented correctly and efficiently. This approach not only improved the efficiency of the screening process but also helped to promote sustainability by making use of existing resources and involving multiple stakeholders in the process.

The CHD screening program employs a comprehensive two-stage approach involving multiple diagnostic methods, trained healthcare professionals, and specialized facilities to identify potential cases of CHD among primary school children. The primary screening methods were a combination of heart examinations focusing on cardiac auscultation using a stethoscope and a 12-lead electrocardiogram conducted by general practitioners and nurses from puskesmas who have been trained. The children identified with abnormal findings in the primary screening were invited to secondary screening using transthoracic echocardiography by cardiologists in district hospitals or *Pusat Jantung Terpadu* (Integrated Heart Center) Dr Sardjito Hospital. The procedure is described in Figure 1.

### ***Implementation: heart abnormalities and CHD identification***

Despite a small refusal and being unable to attend due to fear of covid 19, this screening program shows the benefits of early screening. Twelve puskesmas participated during the first- and second-year periods. Of 6367 children screened, 6116 completed the primary screening procedures (96.1%). The reasons for incomplete screening were refusals and fear of the 12-lead electrocardiogram. In the screening process, 6116 children were screened, and 329 (5.38%) had abnormal findings. Of these 329 children, 260 underwent secondary screening, while 22 refused, and 47 could not attend due to pandemic-related social restrictions. Among the 260 children who completed both primary and secondary screenings, 18 (6.9%) were found to have an abnormality detected through transthoracic echocardiography. These findings indicate the importance of early screening in detecting abnormalities in children, especially during a

pandemic, where access to healthcare can be limited.



**Figure 1. The procedure of congenital heart disease screening for first-grade primary school children (12)**

**Implementation: challenges and opportunities**

Although the health providers involved in the screening program have been trained, lack of confidence, staff turnover, and staff overload due to the COVID-19 pandemic have caused sub-optimal roles of general practitioners and nurses in CHD training. The supervisors from the research team were the main persons who conducted the CHD primary screen rather than the trained puskesmas health personnel. Motivating puskesmas' health providers to be more involved in the CHDs screening program may require several strategies, such as: increasing the training hours with real practical sessions, providing an MoH-accredited certificate that allows the health providers to get credit points to their employees, and ensuring that the knowledge and skills are shared within staff in the same puskesmas to anticipate staff turnover. Another challenge was using a 12-lead electrocardiogram, which could be complicated to use by newly trained health providers. Developing simpler equipment, like a 6-led electrocardiogram, could strengthen the role of puskesmas' health providers.

**Incorporation: policy planning & formulation**

Collaborative efforts and policy support are crucial for improving public health outcomes. The research team has consistently conducted a series of discussions with the expertise, stakeholders (i.e., Yogyakarta Provincial Research Council, Yogyakarta provincial health office, Yogyakarta provincial education office), puskesmas, and school staff to explore possibilities of conducting a wider screening program. Building on these discussions, the team also engaged in an advanced conversation with the Governor Office, including the governor, bureau of law, and bureau of research. As a result of these discussions, the Governor agreed that early detection of CHD in children could improve the Yogyakarta people's quality of life. Subsequently, further meetings were held to discuss more technical matters, such as the form of regulations backed by the academic paper and the parties involved in the preparation. These meetings involved the Health, Education, Youth, and Sports offices and Law Bureau at the provincial and district levels. Following these meetings, the research team completed an academic paper, which was discussed at the law bureau in April

2021. This led to the issue of Yogyakarta Governor Regulation 103/2021 on the Provincial Action Plan on Community Health Movement, which mandated the provincial social security agency (Bapel Jamkesos) to cover the cost of secondary screenings and initial treatment not covered by national health insurance. Since the implementation of this regulation, the screening program has been started, and up to August 2022, 20 children identified with CHD through the screening program have received treatment.

## DISCUSSIONS

This study showed how an academic-led study on CHD screening programs for primary school children, through a continuous and relentless approach to engaging multi-stakeholders, has succeeded translated into policy. The study involved a significant proportion of the affected population, showed direct benefit to the health providers by training them in the CHD screening method, and engaged local stakeholders from multiple sectors (i.e., education and health) and the local leader. The research team was academic staff in the local university and teaching hospitals (Universitas Gadjah Mada and Sardijto hospitals) and published a sound evidence-based finding from the study, which was highly needed to support the establishment of local regulation.

Strategic policy planning can have an impact on policy-making. Good planning also involves various sectors so that they can collaborate to produce firm policy [15,16]. This article demonstrates good planning and execution, from consolidation and implementation to incorporating such programs into the existing policies. The primary CHD screening is feasible to be performed yearly in first-grade elementary school students and can be integrated as a single activity with the mandatory annual health screening program. The secondary screening by transthoracic echocardiography was easily accepted by the school students. The transthoracic echocardiography was performed without any difficulties. However, the willingness of school students and parents to get secondary screening required some motivation because they needed extra time to come to the district hospital or our heart center.

Congenital heart disease (CHD) is a heart defect from birth. The number of patients with CHD in adulthood in Yogyakarta and Indonesia indicates a lack of early detection/screening or diagnosis in early childhood, even in infants. This causes many CHD patients to go undetected and too late to be treated.

Thus increasing morbidity and mortality, as well as the high economic burden due to expensive and long treatment due to complications [17]. Screening with 12-lead electrocardiography can help detect children with CHD who have no symptoms [14].

Currently, no simple and effective CHD screening program is implemented in Indonesia. The role of this screening program is important, considering that this program can prevent high morbidity and mortality rates. The screening program using the 12-lead-electrocardiography and auscultation method is expected to be inexpensive, simple, and efficient screening program. Through *Peraturan Gubernur DIY 103/2021 tentang Rencana Aksi Daerah Gerakan Masyarakat Hidup Sehat*, this program is expected to be implemented in all elementary schools in Yogyakarta. All stakeholders involved are expected to be able to implement this program.

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