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Health Management Information System to Strengthen Congenital Hypothyroid Screening Program in Jakarta, Indonesia

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Abstract

Congenital Hypothyroid Screening (CHS) is critical for early diagnosis and treatment, yet Jakarta faces challenges such as delayed reporting and limited data reliability in its program management. This study employed Design Science Research (DSR) methodology to develop and evaluate a digital health management information system (HMIS) for CHS using DHIS2. Evaluation, using the UTAUT2 model, revealed that Performance Expectancy and Facilitating Conditions are primary drivers of user adoption, highlighting the need for institutional support and training. DHIS2 has significantly improved CHS data management by automating aggregation and visualization, enhancing data-driven decision-making despite initial transition challenges. Future efforts should prioritise interoperability, data governance, and workflow optimisation to ensure long-term sustainability and seamless integration.

Keywords: congenital hypothyroidism, newborn screening, digital health, health management information systems

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1.0 Introduction

Congenital Hypothyroidism (CH) is the most common preventable cause of cognitive disability worldwide, with an incidence of 1 in 2,000 to 1 in 4,000 live births (Kurniawan, 2020; Pulungan et al., 2024). CH results from absent or underactive thyroid gland function at birth, impacting metabolism, bone growth, cardiovascular function, thermoregulation, neural development, and brain maturation. Without timely intervention, thyroid hormone deficiency in early life can lead to severe outcomes, including stunting and irreversible intellectual disability. While some cases are transient, permanent CH requires lifelong treatment, posing long-term financial and emotional burdens on families and the health system. In Indonesia, comprehensive national data on CH remains scarce. A multicenter study in Bandung and Jakarta reported an incidence of 1 in 2,513, which is higher than the global average, while more recent research in 2020 estimated a national prevalence of 1 in 1,167 (Pulungan et al., 2024). Despite these figures, reliable and detailed prevalence data for Jakarta is lacking. Importantly, over 95% of infants with CH are asymptomatic at birth (Uthayaseelan et al., 2022), and by the time clinical signs emerge, cognitive damage may already be irreversible. Therefore, universal newborn screening before the onset of symptoms is essential.

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Indonesia's Ministry of Health mandates CHS for all infants (PMK No. 78/2014), to be conducted within 48–72 hours after birth. Weekly reports must be submitted by both public and private healthcare facilities (Peraturan Menteri Kesehatan Nomor 78 Tahun 2014 Tentang Skrining Hipotiroid Kongenital, 2014). In Jakarta, the Provincial Health Office (PHO) oversees CHS implementation across hundreds of health facilities (Peraturan Gubernur Nomor 57 Tahun 2022 Tentang Organisasi Dan Tata Kerja Perangkat Daerah, 2022). However, the program has faced persistent issues, including delayed reporting, data inaccuracy, and poor utilization of collected data—largely due to reliance on paper-based systems. To address these challenges, Jakarta PHO adopted DHIS2, that enables real-time data entry, visualization, and analysis. This system improves data accuracy, facilitates timely decision-making, and supports effective program monitoring. Despite CHS's importance, no previous studies in Indonesia have explored the use of a digital solution for CHS reporting. This study addresses that gap by evaluating a DHIS2-based CHS system tailored to local needs, aiming to strengthen digital reporting, improve screening outcomes, and inform public health strategy.

2.0 Literature Review

Congenital hypothyroidism (CH) is the most prevalent preventable cause of cognitive disability, with a global prevalence ranging from 1:2000 to 1:4000 live births (Kurniawan, 2020; Pulungan et al., 2024). Unfortunately, comprehensive national data on CH prevalence in Indonesia is lacking. A multicenter study conducted at Hasan Sadikin Hospital in Bandung and Dr. Cipto Mangunkusumo Hospital in Jakarta reported an incidence rate of 1:2513 among 213,669 neonates screened from 2000 to September 2014, exceeding the global incidence rate of 1:3000 (Pulungan et al., 2020). More recent research in 2024 indicated that the national prevalence of CH in Indonesia is approximately 1:1167 (Pulungan et al., 2024). Despite these findings, precise data on the incidence and prevalence of CH in Jakarta remains unavailable. It is worth noting that Jakarta is the largest metropolis in Indonesia. The province has a 664.01 km² area, including 110 islands. The public health system in Jakarta follows the Indonesian hierarchical system with district, province, and national levels. There are a total of 2,681 healthcare facilities, of which 93 of the facilities and 1 regional lab facility are owned by Jakarta PHO (Kementerian Kesehatan, n.d.). As of June 2023, the population of Jakarta stands at 10,679,951 people. Among this population, there are 145,584 pregnant women and 140,115 newborns (Badan Pusat Statistik Provinsi DKI Jakarta, n.d.). It is crucial to screen this newborn as part of the newborn screening program. Implementing comprehensive follow-up and management protocols for all identified cases after CH screening is also essential.

A Health Management Information System (HMIS) using DHIS2 can enhance the CHS program by enabling timely data entry, integration, and analysis across multiple levels of the health system. Literature highlights that DHIS2 improves data accuracy, reduces reporting delays, and strengthens routine health program monitoring, particularly in resource-constrained (Bhattacharya et al., 2019; Byrne & Sæbø, 2022; DHIS2 Team, 2024; Reynolds et al., 2022). By supporting real-time visualization of screening coverage, follow-up, and treatment outcomes, DHIS2 empowers program managers to make informed decisions and allocate resources more efficiently to improve child health outcomes.

3.0 Methodology

This study employed the Design Science Research (DSR) methodology to develop a health management information system for congenital hypothyroidism screening (CHS) in Jakarta. DSR is an iterative approach that focuses on designing, building, and evaluating innovative solutions to address complex real-world problems (Peppers et al., 2007). Through multiple discussions with programme and data managers, key challenges in the CHS reporting system were identified, and digital health technologies were leveraged to enhance data-driven decision-making. A comprehensive literature review was conducted, involving a structured search of relevant academic databases, government reports, and policy documents. This review gathered insights into CH prevalence, screening policies, and digital health interventions, utilizing keywords such as congenital hypothyroidism, neonatal screening, public health reporting, and digital health systems. The selected literature, including peer-reviewed journals, national health regulations, and previous health information system implementations, was critically analyzed for data completeness, methodological rigour, and relevance to the Indonesian healthcare context. The findings from this review informed the baseline requirements for the CHS health management information system, which were subsequently validated through consultations with health program and data managers at provincial, district, and healthcare facility levels. The system design process was directly guided by the identified stakeholder needs and existing documentation from DHIS2, which has been adopted for CHS reporting in Jakarta. Requirements were gathered through iterative discussions with health officials, data managers, and ICT specialists to ensure alignment with policy mandates and operational workflows. The design incorporated key functionalities crucial for effective monitoring and evaluation of CHS implementation, such as structured data entry, automated report generation, and real-time dashboard visualisations. DHIS2 metadata configurations, reporting structures, and interoperability considerations were thoroughly reviewed to ensure seamless integration within the existing health information ecosystem.

3.1 Health Information Systems Design

Jakarta's health management information system (HMIS), built on the open-source DHIS2 platform, supports data collection, validation, and analysis to enhance service quality (DHIS2 Team, 2024). Deployed as a Java web application with an SQL backend, DHIS2 enables the creation of dashboards and analytical tools for health program monitoring. For CHS implementation, key challenges identified include delayed reporting, poor data quality, and limited data use. Multiple discussions with program and data managers in Jakarta have identified several health system challenges that impede the process of monitoring and evaluating the implementation of congenital hypothyroidism screening (CHS). These challenges include delayed reporting of events, lack of quality and reliable data, limited access

to information and disaggregated data, as well as insufficient utilization of data and information. Three primary criteria for the system emerged from the collaborative design process: scalability, data usability, and the ability of the system to operate in low-resource settings. Scalability involves ensuring that all healthcare facilities possess the capability to submit reports while allowing managers easy access to view these reports. Additionally, interoperability with other systems is an important consideration, given the high demand to communicate data to other stakeholders. Secondly, the system must operate efficiently in environments with limited resources, handling a high volume of messages during reporting times. Lastly, data usability is essential for system adoption, aligning with Jakarta PHO's objective of enhancing the CHS program by increasing data accessibility for managers and important decision-makers. It is crucial to consider how data can be utilized and acted upon, as well as determine which stakeholders require access to original data or summary reports. To ensure the system's effectiveness, a User Acceptance Testing (UAT) process will be conducted, allowing for validation of its functionalities and alignment with the operational needs of healthcare providers, data managers, and policymakers.

Table 1. System Requirements

Category	Requirements	Description	Technical Implementation
Scalability	Multi-facility reporting	Ensure all healthcare facilities can submit reports and managers can access them easily.	Use DHIS2 Data Sets for routine reporting with organisation unit hierarchy to support multi-facility data entry.
	Interoperability	Enable seamless data exchange with other health information systems and stakeholders.	Use DHIS2 Web API for data exchange with external systems.
Data Usability	Real-time access	Provide decision-makers with timely and accurate data for monitoring and evaluation.	Use DHIS2 Event Reports and Event Visualiser to generate real-time analytics.
	Data visualization	Implement dashboards and reports to enhance data interpretation and usability.	Configure DHIS2 Dashboards and Charts for data visualization.
	Role-based access control	Ensure appropriate data access for different user roles, from facility-level staff to policymakers.	Use DHIS2 User Roles and Authorities to manage data access control.
Low-Resource Operation	High-volume data handling	Ensure the system can process and store large volumes of data, especially during peak reporting times.	Optimize DHIS2 Data Store and aggregate analytics tables for better performance.
Security & Compliance	Data privacy & security	Implement encryption and authentication mechanisms to protect sensitive health information.	Use DHIS2 Metadata Access Control and Audit Logs for security compliance.
Stakeholder Collaboration	Multi-level access	Enable provincial, district, and facility-level users to interact with the system based on their roles.	Configure DHIS2 Organisation Units and User Groups to define access levels.
	DHIS2 integration	Align with Jakarta PHO's existing digital health infrastructure for seamless CHS reporting.	Use DHIS2 Capture for patient-level CHS data collection and monitoring.

(Source: Focus Group Discussion in Jakarta Health Office Environment)

3.2 Evaluation Method

The Unified Theory of Acceptance and Use of Technology (UTAUT) is an information technology evaluation model that explains user behaviour (Chang, 2012; Venkatesh et al., 2003). This model is a combination and refinement of eight previously developed models. It posits that user acceptance of technology is influenced by four key dimensions: performance expectancy, effort expectancy, social influence, and facilitating conditions (Bai & Guo, 2022). Performance Expectancy (PE) generally refers to perceptions of ease in management, speed in task completion, performance benefits, and motivation. Effort Expectancy (EE) relates to ease of interaction, complexity, perceived ease of use, and ease of learning. Social Influence (SI) encompasses factors such as family, friends, social circles, and influential individuals. Facilitating Conditions (FC) include available support, knowledge, compatibility, and widespread acceptance. In this study, the UTAUT2 model is applied to evaluate user acceptance of the implementation of the Jakarta Provincial Health Office's Data Warehouse system. A total of 15 questions have been developed, summarizing the four main constructs: performance expectancy, effort expectancy, social influence, and facilitating conditions. Since the study is conducted in DKI Jakarta, the questions have been tailored to specifically assess the DHIS2 used in the Jakarta Provincial Health Office.

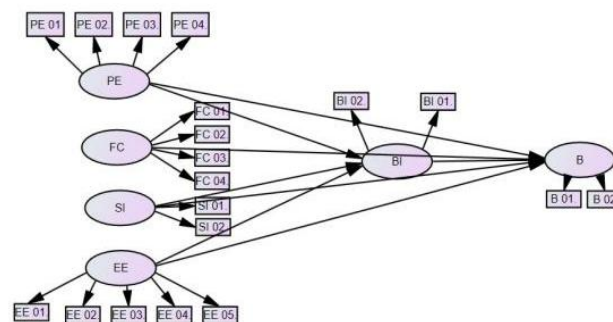


Fig. 1: UTAUT2 Model

(Source: Chang, 2012; Venkatesh et al., 2003)

The questionnaire is designed using open-ended questions based on the variables and indicators in the UTAUT2 model. The study population consisted of data managers at community health centres (*Puskesmas*), clinics, regional public hospitals, and district health offices. Purposive sampling was employed to select a subset of the population, specifically targeting data managers responsible for

recording and reporting data in the HMIS. The sample size for PLS-SEM was determined based on the "10 times rule of thumb," suggesting the sample should be ten times the maximum number of paths leading to a latent variable. With eight paths in this study, the minimum required sample size was 80 respondents ($8 \times 10 = 80$); the actual sample size used was 85. The analysis of respondents' perceptions of the indicators was conducted using the Partial Least Squares Structural Equation Modeling (PLS-SEM) approach with SmartPLS 3.0 software.

4.0 Results and Discussion

At the district/city level, CHS (Congenital Hypothyroid Screening) reporting aggregates data from healthcare facilities based on national guidelines and aligns with the provincial format. Reports include screening coverage, positive results, confirmatory tests, untracked cases, hypothyroidism diagnoses, and treated cases. Program managers monitor these indicators to guide decision-making. Documentation also includes SHK logistics availability. Using DHIS2 via datakesehatan.jakarta.go.id, healthcare and laboratory users collaboratively enter and submit CHS data. Screening alone is insufficient. Besides newborn screening, the handling of CH requires timely diagnosis and accurate interpretation of the results to support adequate therapy and consistent monitoring. Thus, the rate of CHS coverage, the number of positive results, the number of confirmation tests conducted, the count of cases that cannot be traced, and the instances of congenital hypothyroidism with treated cases are regularly monitored.

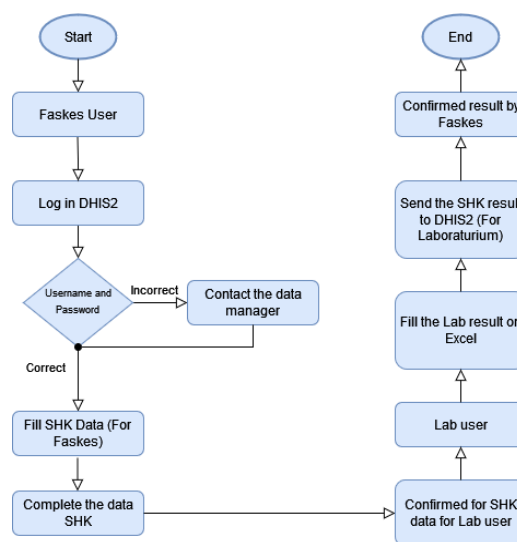


Fig. 2: Congenital hypothyroidism (CHS) Reporting in Health Management Information System

Reporting templates for CHS have been standardized by the Ministry of Health (Peraturan Menteri Kesehatan Nomor 78 Tahun 2014 Tentang Skrining Hipotiroid Kongenital, 2014), requiring submission of both individual and aggregate data. At least 13 forms are used, and completed by different field officers to ensure comprehensive reporting. Aggregate reports at district and provincial levels include nine key variables such as screening rejections, specimen transport, CHS results, and treatment data. Two DHIS2 electronic forms were developed: individual data via the Capture feature and aggregate data via Data Entry. Individual forms are split into five sections by role, while aggregate forms include clear variable definitions to support data quality (see Fig 3 and Fig 4).

Fig. 3: Individual Data Form Using DHIS2 'Capture' Feature

No	Titik Data	Titik	Definisi Operasional
1	Jumlah Bayi Baru Lahir		Jumlah Bayi Baru Lahir: jumlah bayi yang lahir setiap di fasilitas kesehatan sesuai pada periode pelaporan.
2	Jumlah sampel diperiksa (menggunakan prosedur APED)		Jumlah sampel diperiksa (menggunakan prosedur APED): jumlah bayi yang diperiksa SHK dengan sampel SHK oleh Badan senter dengan menggunakan prosedur APED (menggunakan B3-DF 5123) dan dikirim ke Laboratorium B3-DF pada periode pelaporan.
3	Jumlah sampel diperiksa (menggunakan prosedur APED)		Jumlah sampel diperiksa (menggunakan prosedur APED): jumlah bayi yang diperiksa SHK dengan sampel SHK oleh Badan senter dengan menggunakan prosedur APED (menggunakan B3-DF 5123) pada periode pelaporan.
4	Jumlah sampel diperiksa (menggunakan prosedur APED)		Jumlah sampel diperiksa (menggunakan prosedur APED): jumlah bayi yang diperiksa SHK dengan sampel SHK oleh Badan senter dengan menggunakan prosedur APED (menggunakan B3-DF 5123) pada periode pelaporan.
5	Jumlah Sampel Bayi Baru Lahir diperiksa SHK dengan hasil positif		Jumlah Sampel Bayi Baru Lahir diperiksa SHK dengan hasil positif: jumlah sampel bayi baru lahir yang diperiksa SHK dengan sampel SHK oleh Badan senter (menggunakan prosedur APED) dengan hasil SHK positif pada periode pelaporan dan hasil dikirim.
6	Jumlah bayi SHK Positif Baru		Jumlah bayi SHK Positif Baru: jumlah bayi baru lahir yang diperiksa SHK dengan hasil positif dan dikonfirmasi berdasarkan temuan hasil PCTP negatif kasus bayi baru lahir PCTP, berdasarkan data spesialis anak kasus bayi.

Fig. 4: Aggregate Data Form Using DHIS2 'Data Entry' Feature

One of the main responsibilities of Jakarta health offices is the compilation of screening results to track and assess how CHS is being implemented in the area. Continuous monitoring activities are carried out to supervise the execution of the CHS program. The

main objective of monitoring is to enhance program implementation by identifying and addressing activities that fall short of service standards. Furthermore, monitoring functions to incentivize healthcare personnel and program administrators to expand coverage. Evaluations need to occur at least annually and are harmonized with other initiatives. Thus, it is important for the Jakarta PHO to have appropriate tools to support the monitoring and evaluation processes. Leveraging DHIS2 built-in analytical instruments including reports, graphs, spatial representations, pivot tables, and interactive panels, a CHS program monitoring dashboard is developed as shown in Fig 5. For detailed monitoring of individual data levels, feature Event Reports is available as illustrated in Fig 6.

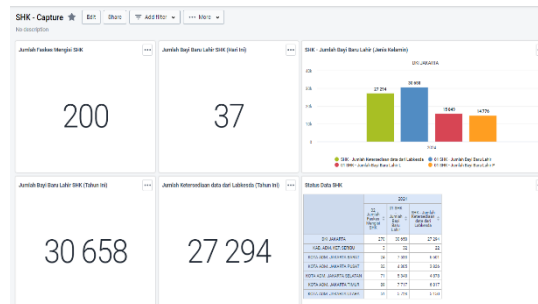


Fig. 5: CHS Program Monitoring Dashboard

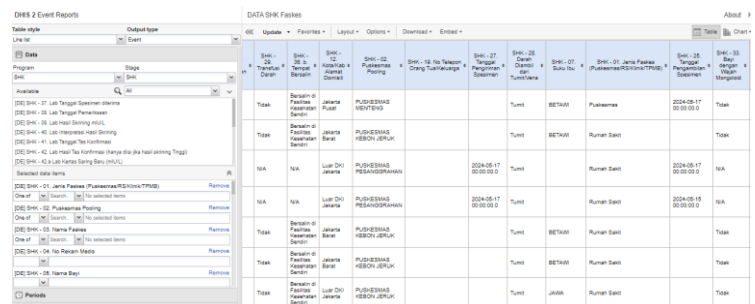


Fig. 6: CHS Event Report for Individual Data

Based on the UTAUT2 evaluation, the implementation of a Health Management Information System (HMIS) has played a significant role in strengthening the monitoring and evaluation of the Congenital Hypothyroidism Screening (CHS) program in Jakarta. According to recent evaluation findings, user intention significantly influences user behaviour (Direct Effect = 0.390; $p = 0.047$). The most influential factor driving user intention is Performance Expectancy of the HMIS (Direct Effect = 0.584; $p = 0.003$), while Facilitating Conditions provided by the Provincial Health Office are the strongest predictor of actual system use (Direct Effect = 0.417; $p = 0.041$). Indirect effects on user behaviour through user intention are also notable, especially for Performance Expectancy (Indirect Effect = 0.247) and Effort Expectancy (Indirect Effect = 0.101), indicating the importance of both user perception and organizational support.

National implementation of the CHS program began with the issuance of Ministry of Health Regulation No. 78/2014. However, by 2022, national CHS coverage remained critically low at just 2.3% (Pulungan et al., 2024). To address this, the Ministry of Health integrated CHS services into Indonesia's Universal Health Coverage (JKN) scheme. Jakarta, which had previously conducted pilot studies between 2000 and 2008, expanded CHS to all healthcare facilities in 2022 (Biro Komunikasi dan Pelayanan Publik, 2022; Peraturan Menteri Kesehatan Nomor 78 Tahun 2014 Tentang Skrining Hipotiroid Kongenital, 2014; Pulungan et al., 2024). Recognizing the need for real-time data and streamlined reporting, the Jakarta Provincial Health Office (PHO) adopted DHIS2, a web-based open-source HMIS platform, for digital data capture and reporting. Standard operating procedures for user registration and data submission were developed, and the reporting of individual-level data was initiated in 2023 through the Capture feature in DHIS2. Reports are submitted by designated Puskesmas serving as "pooling" facilities.

During the initial rollout, technical issues were encountered, particularly errors in data counts of Data Elements and Data Indicators after report submission. These errors were regularly communicated to the Centre of Data and Information Technology team at the PHO. To address these challenges, a dedicated group of experts was assigned to administer the system, ensuring continuous support and troubleshooting. With the apparent success of the system, complete execution of the CHS documentation utilizing HMIS was instituted in 2024. As a result, all 197 hospitals, 44 Puskesmas, and 1 regional laboratory centre are now obligated to register for an account. At least two distinct electronic forms are required for submission: individual data on a day-to-day basis and aggregated data every month. The digitalization of reporting, monitoring, and evaluation activities using a digital health tool is crucial for strengthening the CHS program, supporting data accuracy, facilitating real-time monitoring, and enabling more effective program management and decision-making. The available CHS program data in Jakarta's HMIS is regularly utilized to identify challenges and inform the formulation of solutions.

4.0 Conclusion and Recommendations

The implementation of a digital Health Management Information System (HMIS) using DHIS2 for Congenital Hypothyroid Screening (CHS) in Jakarta has addressed major limitations of paper-based reporting, including delays, inefficiencies, and data loss. By enabling real-time data entry and access by healthcare facilities and laboratories, the system has improved data accuracy, reduced administrative burden, and enhanced monitoring at the provincial level.

Evaluation using the UTAUT2 model revealed that user adoption is primarily influenced by Performance Expectancy and Facilitating Conditions, highlighting the importance of perceived system benefits and institutional support. Factors such as Effort Expectancy and Social Influence also indirectly affect user intention, reinforcing the need for usability and training. Despite initial challenges, DHIS2 has significantly strengthened CHS data management through automated aggregation, visualization, and analysis. This aligns with national efforts to expand CHS coverage under the JKN scheme. Jakarta's success provides a model for scaling digital health interventions in newborn screening. To sustain progress, future priorities include improving interoperability with national systems, refining workflows,

strengthening data governance, and implementing routine data quality checks. These steps are critical for maximizing the HMIS's long-term impact and improving health outcomes.

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Paper Contribution to Related Field of Study

This study makes a significant contribution by being the first in Indonesia to explore the implementation of a dedicated Congenital Hypothyroid Screening (CHS) application, demonstrating novelty in its design and integration with existing ICT infrastructure and DHIS2. Its successful implementation has strengthened CHS data management, improved reporting efficiency by addressing paper-based challenges, and provided a scalable model for nationwide digital health interventions.

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