



Intelligent platform for surveillance of neonatal congenital heart disease: big data and parental self-report based innovative strategies

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Background: The neonatal congenital heart disease (NCHD) screening program has advanced in China. However, there are still some missed cases after discharge from maternity hospitals. Moreover, parents' cognitive level and compliance with congenital heart disease (CHD) management are limited. The current disease reporting system, which relies on medical personnel, encounters issues with data omission and misreporting, exacerbated by the manual follow-up process's inefficiency. Involving parents in NCHD management mitigates challenges arising from population mobility, deepens parents' comprehension of the disease, and promotes active data input, ultimately enhancing health management efficiency.

Methods: We performed the key technologies, design, and architecture of the developed platform. It explores the applications of Mobile Health (M-Health) based on big data technology, representing an innovative approach to monitoring CHD that emphasizes the integration of advanced technologies such as data integration, online consultation, message reminders, and parental involvement. A feasibility assessment was conducted, involving interviews with medical staff, to evaluate the practicality and effectiveness of the system. Additionally, a preliminary analysis of platform usage was undertaken.

Results: The platform demonstrated successful integration across the entire CHD management spectrum, including Parent Registration, Screening Phase, Diagnosis Phase, and Treatment Phase. It consists of a mobile APP and a back-end data management system. Parents input information on the platform, which is uploaded to the system. Then, the back-end data management system monitors the case course and provides regular reminders for the treatment and valuable related knowledge for CHD. Based on feedback from medical staff, valuable suggestions for platform enhancement were identified. A total of 891 infants from June 1, 2023, to August 31, 2023, were enrolled at two hospitals in China.

Conclusions: This big data management platform sets a commendable example for the comprehensive management of NCHD. Continuous improvement in technological proficiency and security safeguards will likely enhance the platform's widespread and profound impact in future clinical practices. Timely feedback and adjustments during usage are crucial to ensuring the platform's effectiveness and adaptability, thereby

guaranteeing the realization of the intended design effectiveness.

Keywords: Big data; data mining; neonate; congenital heart disease (CHD); screening

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Introduction

Neonatal congenital heart disease (NCHD) is a group of birth defects that result from impaired formation or abnormal development of the heart and blood vessels during embryonic development. The prevalence of congenital heart disease (CHD) ranges from 8–9/1,000 live births (1,2). Neonatal major CHD (mCHD) requires invasive intervention before 1 year of age (3). Thus, early detection might improve the outcome of newborns, reducing the mortality rate.

The Department of Maternal and Child Health of China's National Health Commission launched the first NCHD screening program on July 31, 2018, using the “dual-index method” (pulse oximetry and cardiac murmur auscultation) to screen newborns from 6–72 h after birth for CHD in 24 provinces nationwide. The high detection rate of neonatal mCHD and sensitivity of the “dual-index

method” has been confirmed in two prospective studies, with large samples, conducted in China (4,5). To further improve the accuracy and efficiency of pulse oximetry and cardiac murmur auscultation, we have developed an intelligent and automated screening instrument for NCHD to realize the intelligence and homogenization of the screening process (6).

Challenges in the traditional management of NCHD

Although the screening program has been carried out successfully nationwide, several problems need to be solved, such as some newborns with positive screening not diagnosed by echocardiography, some missed CHD cases, untimely transportation, lack of follow-up information, and difficulties in follow-up. According to the Chinese information management system for NCHD screening from 2019–2021, a total of 44,273 newborns were diagnosed with CHD in the pilot provinces. The incidence rate of NCHD is 3.66‰, which was lower than 8.9‰, as reported previously (7), implying that some of the cases were missed. The overall echocardiography rate (number of newborns with positive screening undergoing cardiac ultrasound examination/number of newborns with positive screening ×100%) in most provinces was only 67.11%. In addition, only 2,984 newborns with CHD underwent surgery or invasive intervention; however, the specific condition was unavailable, which was not helpful for the follow-up and health management of CHD patients.

According to the field research and reports from each province in 2019, the low echocardiography rate and the low number of surgical/invasive interventions could be attributed to the following factors: (I) lack of adequate education: parents lack awareness about the screening, diagnosis, and treatment of CHD, neglecting further diagnosis and treatment; (II) failure to accurately match their identity: parents not carrying the referral for positive screening or using a new name during transport to the hospital; (III) missing or incomplete disease records: health providers did not fill in the information system

Highlight box

Key findings

- This paper presents a detailed architecture and workflow of the platform, which is the first big data management platform for neonatal congenital heart disease (NCHD) screening, diagnosis, treatment, and follow-up.

What is known and what is new?

- Even though the screening program has been successfully implemented across the country, some cases remain to be missed or lost for follow-up. Parental compliance with NCHD management is also limited.
- An Intelligent Platform is established to improve parents' cognitive level and compliance with follow-up diagnosis and treatment of congenital heart disease (CHD) based on the self-report mode with parents' participation and assistance in management.

What is the implication, and what should change now?

- This platform would improve the efficiency of NCHD management.
- Initiatives should be taken to encourage and educate parents about the importance of their active participation through self-reporting.

after diagnosis and treatment for the positively screened newborns.

The compliance of parents for CHD management is low under the current health education implementation, wherein healthcare providers introduce the significance of CHD screening, diagnosis, and treatment to parents only through leaflets or informed consent immediately after delivery. Research has discovered that the mental health of parents is correlated with the psychosocial functioning and quality of life for their children with CHD (8). Therefore, incorporating psychoeducation focused on parents, more knowledge about CHD, and parental involvement in CHD management can yield favorable effects on children's initial diagnosis, prognosis, and overall quality of life.

Presently, the data on NCHD screening, diagnosis, and treatment are dependent on the information system filled in by the medical staff; thus, differences in compliance among the medical staff in different regions of the country, including omission and misreporting, are inevitable. The diagnosis and treatment data of NCHD in Taiwan and other countries/regions are realized by telephone, follow-up visits, or links and accurate matching of various databases (9-13), increasing the burden on medical staff and causing some data loss.

Infant and child mortality related to critical CHD (CCHD) is still high in developing countries due to delayed diagnosis and negligent medical record management (14). Simultaneously, there is no uniformly managed birth defect database or autopsy data in China to verify the causes of infant death that might be related to CHD. Moreover, China's large population base, large population mobility, and uneven distribution of medical resources between urban and rural areas make it challenging to identify missed cases by studying all the hospitalized cases of CHD. Access to medical resources in some poor areas is also limited (4).

Therefore, establishing a big data management platform for NCHD screening, diagnosis, treatment, and follow-up is an urgent requirement to improve parents' cognitive level and compliance with follow-up diagnosis and treatment of NCHD based on the self-report mode with parents' participation and assistance in management. Also, cooperation with medical staff to jointly improve the follow-up diagnosis, treatment, and management level of NCHD screening program is essential to realize the integrated management of NCHD.

Mobile health (M-Health) APP

The development of M-Health makes medical services and

health management intelligent and informative. In recent years, studies on M-Health APPs for different groups and diseases have been carried out, mainly focusing on the self-management of diseases and self-reporting by the patients (15-19). In M-Health, mobile devices or platforms can be used for clinical health data collection that can then be disseminated to researchers, medical personnel, and patients for health condition monitoring. M-Health also offers support for the direct provision of healthcare through telemedicine, promotes medical service coverage, and improves the quality of healthcare services using big data technology for high clinical diagnostic efficiency and treatment compliance (20). In the management of NCHD, M-Health can realize data linkage between maternity and pediatric hospitals to diagnose and treat CHD in case of missed diagnosis and lost follow-up (21,22). Thus, pioneering technology and M-Health can be expected to address several aspects in the near future.

Electronic medical record realizes efficient management of health data

Huge and complex healthcare data sets need large data tools for data management. An electronic health record is a digital version of patients' medical records. Authorized users can access patients' health information (23,24).

The electronic medical record system has been used in clinical practice, which underlies the intelligent information management of cases. A general lack of a national unified management system for birth defect diseases (for example, CHD) exists in most countries. The current information management for NCHD screening, diagnosis, and follow-up in most studies is effectuated via data filling based on the system of the state/district government in each country. For example, no national birth defects surveillance system has been established in the United States, but most states have their own surveillance systems that vary according to the surveillance entity (such as the health department), the surveillance target, the method of diagnosis, the age of the child, the type of defect, and the transmission of information between databases (25).

In China, some hospitals are responsible for their own information management systems, purchased or developed according to the actual demand; usually, the system suppliers are uneven. Therefore, data interconnection among hospitals is difficult. Establishing the exchange standard of massive data and unified management of medical records is an urgent issue to utilize the advantages of M-Health.

Early-warning technology and disease diagnosis based on big data

Data mining technology predicts or classifies based on historical data, which conforms to the development trend of evidence-based medicine and is used in medical diagnosis (26). With the global outbreak of coronavirus disease-2019 (COVID-19), relevant applications of data mining in disease prediction have arisen rapidly. Medical records, clinical symptoms, geographical space, and time data could be used for predictions and draw inferences about outbreaks and also help identify cases, including the likelihood of the infection and the number of people likely to be affected in the future, to take timely action for control of the outbreak (27,28). Such data segmentation-based method would predict the disease outbreaks faster than the classic clinical studies (29). In disease diagnosis, big data technology uses various algorithms and mines relevant disease data based on a large sample of medical examination results, combining the results of several clinical practices and experts' experiences to simulate the predictive diagnosis of disease by experienced doctors and gain accurate diagnosis and treatment suggestions (26). Guo *et al.* (30) utilized machine learning (ML) technology and data mining algorithms to predict postoperative coagulation function in children with CHD. Demographic characteristics and laboratory test results were collected from electronic medical records. This research has identified key features that can assist doctors in predicting the risk of postoperative coagulation abnormalities in children with CHD and facilitating early clinical intervention.

The gold standard for the diagnosis of NCHD is cardiac ultrasound; however, a specific degree of omission and misdiagnosis is persistent. Also, the cost of echocardiography is high. Cardiac murmur auscultation and clinical examination assist in the diagnosis of CHD (4,31). To reduce the subjectivity of manual auscultation, Xiao *et al.* (32) collected and annotated a volume of heart sound recordings from newborns and children to organize a pediatric heart sound dataset and developed a deep-learning-based computer-aided pediatric CHD diagnosis system using convolution neural network (CNNs) models, thereby improving the efficiency and accuracy of diagnosis. Moradi *et al.* (33) proposed a methodology for weak labeling of medical images that matched the echocardiographic images and the data set of diagnostic sentences for accurate diagnosis.

Online consultation and message reminder

Users can communicate with doctors online to obtain

medical consultation services, saving their time in offline services. These platforms can integrate high-quality medical resources and enhance patients' medical experience (34-37). However, the qualifications of consultants or doctors and the quality of responses are yet a major concern. By April 2020, the online consultation team of Children's Hospital of Fudan University in Shanghai, China, has served 12,847 person-times with extensive consulting services.

In addition to the traditional doctor-patient communication, M-Health enhances patients' accessibility to health services and expands its clinical application. Several studies (38,39) have used message reminders to send information to target groups in order to increase the level of health literacy, including appointment reminders and health information. For families who have children born with CHD, regular hospital appointments are a common practice (40). However, no online consultation platform and message reminder function has been established for NCHD. Complications might occur in those who have undergone percutaneous closure, a low-risk intervention (41). If online consultation is feasible, parents can pose their queries online and report any complications that may arise post-surgery. Additionally, doctors can keep track of special cases.

Establishment of an intelligent management platform for NCHD

Our intelligent management platform for NCHD uses the technical advantages of M-Health. It can realize message reminders, big data-based disease warnings, online consultations, and help with disease diagnosis. Finally, the primary goal of the system is to establish a NCHD screening, diagnosis, and follow-up system that can be popularized nationwide and worldwide.

Hitherto, only a few studies have described the construction of an intelligent platform for CHD. American Health Resources and Services Administration (HRSA) funded the CCHD screening demonstration projects at \$300,000/year for establishing a state-level electronic system to collect, report, and analyze the results of CCHD screening systematically based on the guidelines between the state public health department, hospitals, and/or birth facilities. This system develops and delivers educational programs about CCHD screening, counseling, testing, follow-up, treatment, and specialty supportive services (42).

Big data management for NCHD has not been reported in China, and the construction of intelligent information management systems for other pediatric-specific diseases

<p style="text-align: center;">Strengths</p> <ul style="list-style-type: none"> • Ease of use • Data integration • Innovative functions • Parental involvement • Delivering scientific knowledge • Early detection 	<p style="text-align: center;">Weaknesses</p> <ul style="list-style-type: none"> • Technological issues • Data security • Ethical concerns
<p style="text-align: center;">Opportunities</p> <ul style="list-style-type: none"> • Patient empowerment • Healthcare efficiency • Upgraded functions • Research advancements 	<p style="text-align: center;">Threats</p> <ul style="list-style-type: none"> • Data breaches • Limited resources • Competitive landscape

Figure 1 SWOT analysis of the information platform.

has been rarely reported. Wang *et al.* (21) published a cloud-based platform for NCHD screening management system in 2021, which realized data docking between maternity and pediatric hospitals. Nonetheless, information filling and uploading still rely on the medical staff without the pioneering application of information technology and data management. The research in the field of pediatric disease-related applications is only limited to the value in clinical practice (22,43-45). It is imperative to establish an information platform dedicated to the management of NCHD with the aim of improving healthcare efficiency, facilitating early detection of NCHD, and ultimately enhancing the quality of life for affected individuals.

SWOT analysis for adopting information platform in healthcare

The SWOT analysis is a strategic planning technique that is employed to evaluate the project's strengths, weaknesses, opportunities, and threats (46). The information platform stands out due to its several key advantages. In order to achieve widespread promotion and application in clinical practice, a system must be easy to learn and highly efficient. This is referred to as "usability", which is determined by how effectively a product can be used by specific users to achieve specific goals in a specific context of use. A user-friendly graphical user interface (GUI) has the potential to entice a substantial number of users, and the access to menus must be effortless and straightforward (20,47). With its user-friendly interface, the ease of use ensures that healthcare professionals and parents can easily access it, promoting widespread adoption. The platform is renowned for its proficiency in data integration, offering a holistic perspective on a neonate's health history, thereby

aiding in well-informed healthcare decisions. It also provides healthcare providers with advanced tools by offering innovative functions driven by big data. Parents can access health information on the platform to enhance their understanding of CHD. By means of self-reporting, parental involvement promotes a collaborative approach, thereby improving data sharing and integration, as well as parent engagement. The platform's intelligent algorithms can further facilitate the early detection of CHD, ultimately enhancing patient outcomes.

Despite the offered benefits, the usability challenges in M-Health APPs were technological issues, necessitating regular evaluation and monitoring for adjustment and improvement of the tool (20). The use of big data in managing health information has the potential to improve public health surveillance; however, it also presents substantial challenges. The amalgamation and evaluation of extensive health datasets can result in the involuntary identification of individuals, posing a risk to user privacy. Even within healthcare organizations, employees who have access to large data repositories can potentially compromise data security. To reduce security threats, it is necessary to implement certain measures, including: (I) Implementing strong data encryption techniques for both transit and at-rest data to guarantee that only authorized users have access to confidential information (48). (II) Ensure that both the systems and data management processes adhere to the regulations and legal constraints and requirements (49). (III) Security testing is critical for APP developers to identify security and privacy vulnerabilities. Potential security threats, such as unauthorized access, tampering with health data, or reporting invalid data, are expected to be resolved (50). Additionally, the collection and utilization of personal health data for medical care-related purposes may give rise to ethical concerns (51). Therefore, users must be provided with comprehensive details regarding the intended applications of their data, and they must provide active consent for these applications prior to data collection and processing. The SWOT analysis is displayed in *Figure 1*.

Our big data management platform for NCHD screening, diagnosis, treatment, and follow-up is the first intelligent management platform for the whole process to be established and incorporated into the self-report and management of parents. Reliable big data of NCHD screening, diagnosis, treatment, and follow-up can be obtained, which can dynamically summarize and analyze the incidence, operation, cure, and survival rates, of NCHD, answer, the false-negative rate, and the cost-efficiency of

NCHD screening. We present this article in accordance with the SQUIRE reporting checklist (available at <https://pm.amegroups.com/article/view/10.21037/pm-23-45/rc>).

Methods

Key technologies

Efficient information search and high-precision data analysis based on big data

The system designed in this study is based on the test results, especially data or information related to NCHD, and diagnosis standards.

Effective data mining needs high-quality data, which involves initial information processing through client-server, including simplifying the original data set and eliminating the incomplete and inconsistent data for standardization. Then, the data are transmitted to the server through the Internet, and the information in the diagnosis and treatment knowledge base is compared with the big data mining rules. Then, intelligent analysis is conducted based on big data mining rules and a diagnosis and treatment knowledge base. Finally, the diagnosis opinions and treatment suggestions are provided to the parent client-server.

The back-end data management of this information platform is operated by the hospital, which could carry out data statistics, real-time monitoring of the screening and diagnosis, and data management of NCHD in the pilot region. The system adopts support vector machine, mathematical statistics, parameter sensitivity analysis, neural networks, clustering algorithms, and other methods. Based on the data pool of NCHD characteristics, the system can provide intelligent diagnosis opinions and treatment suggestions for CHD based on the screening and ultrasound results of specific newborns to achieve early diagnosis and treatment. It would also help balancing and deployment of medical resources in the region, improve the efficiency of treatment, and further realize the data statistics on the incidence rate, treatment methods, cure rate, and medical resource utilization of NCHD, thereby underlying the targeted formulation of regional medical policies (*Figure 2*).

Medical data storage, transmission security, and multi-interface and multi-system interaction technology

This information platform plans to realize data docking between maternity and pediatric hospitals, sharing diverse information, such as the test result of screening,

echocardiography, and the surgical treatment of CHD. The platform plans to adopt a modular architecture, which can be adjusted quickly according to the interface type and complete the smooth collection of data. In addition, this information platform plans to cover all NCHD-related data in several regions across China. Also, data security is pivotal. Therefore, various measures, such as hardware protection and software verification, will be implemented to achieve medical data security in the research and development process.

Whole-course case management and early warning technology of NCHD

The whole-course management of specific processing sessions involves CHD screening, diagnosis, surgery, and follow-up after discharge from the hospital. Thus, it is essential to focus on the whole process and realize the whole-course case management using high technology, which improves the efficiency of CHD screening, diagnosis, and treatment.

The information system provides early warning and message reminders based on big data analysis of individual situations, which can greatly avoid the timely treatment of potential disease and improve the prevention and treatment level of NCHD.

Expected goals after the launch of the management platform

- (I) Standardized management of NCHD screening, diagnosis, treatment, and follow-up procedures to achieve a low rate of missed screening, missed cases, and loss to follow-up.
- (II) Based on big data analysis, data statistics of NCHD incidence, treatment methods, cure rate, and utilization rate of medical resources are accessible in the pilot regions, helping in the targeted formulation of regional medical policies.
- (III) After finishing the stage platform testing and application in pilot hospitals, a national demonstration intelligent management platform for NCHD screening, diagnosis, treatment, and follow-up will be constructed, which can be widely promoted and applied and used for the screening of other neonatal diseases in the future.

Feasibility assessment

During the design and construction of this information

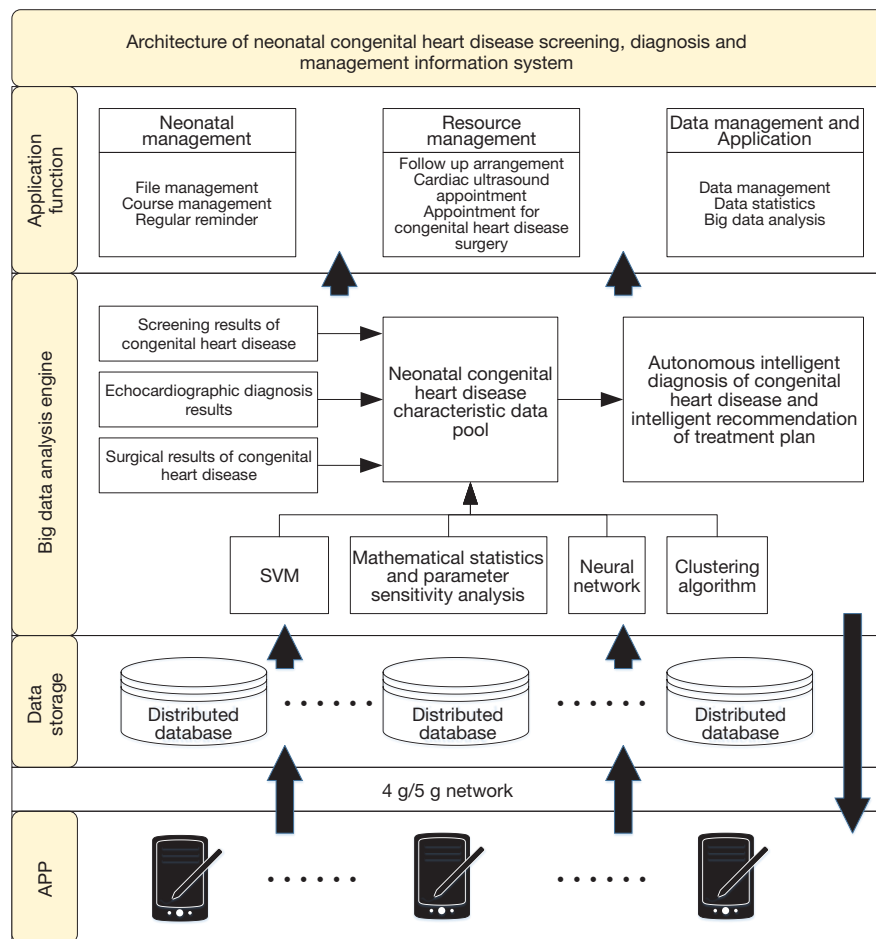


Figure 2 Architecture of the information system. SVM, support vector machine.

platform, interviews were conducted with some medical staff to collect constructive suggestions. We also initiated the initial trial run of our platform at two hospitals in China. All parents were given informed consent forms and used this platform voluntarily. There was no limitation for registration. We analyzed the information provided by parents and the verification process results obtained from the hospital management system. The screening and diagnosis data of NCHD from June 1, 2023, to August 31, 2023 were collected.

The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study was approved by the Research Ethics Committee of the Children’s Hospital of Fudan University, Shanghai, China ([2021]141). All parents of participants used this platform voluntarily and provided informed consent.

Results

System description

The information management platform consists of a mobile APP and a back-end data management system. Parents input information on the platform, which is uploaded to the system, and the medical staff monitor the condition of newborns in the back-end data management system. In cases where information input is incomplete, the system sends reminder message or conducts follow-up actively via phone to inform parents about the need for their newborn to undergo diagnosis or treatment. The data flow is shown in *Figure 3*, corresponding to the parent client-server and the medical staff client-server, respectively. The information platform is connected to the current screening system. It can realize the information

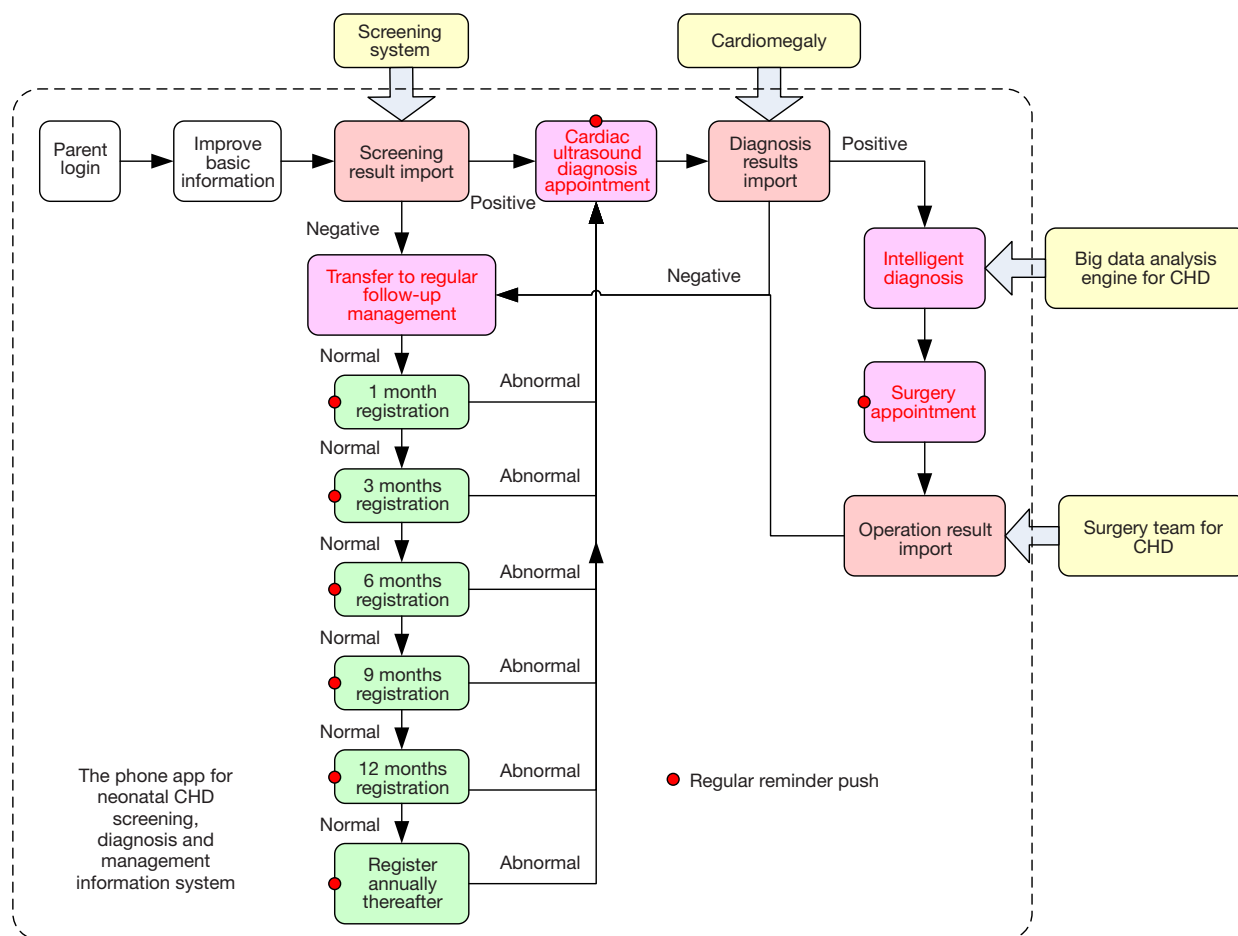


Figure 3 Mobile APP data flow. CHD, congenital heart disease.

locking of cardiac ultrasound examination and treatment, realizing the automatic data import, and avoiding bias from manual import.

The back-end data management system collects data through the APP and establishes nascent files. It also monitors the case course and provides regular reminders for the treatment and valuable related knowledge for CHD.

Big data management can help healthcare institutions in creating extensive databases of CHD patients. By monitoring clinical data of newborns, it can provide CHD-related knowledge to parents, enhancing their cognitive level of this condition. This, in turn, facilitates early detection of CHD and increases the likelihood of positive cardiac ultrasound screening for newborns. Furthermore, by analyzing a vast array of newborn data, healthcare institutions can gain deeper insights into the progression of newborns' conditions. Parents can also seek advice about their newborn's health issues online on the

platform and share pictures. Medical experts will provide prompt responses through the platform. In cases where the newborn's condition is too complex to handle online or if online consultations prove ineffective, parents will be advised to seek offline medical attention.

NCHD files

Parents would be asked to fill in their personal information after logging in the system (*Figure 4*): the newborn's name, date of birth, gestational age, gender, weight, delivery mode, maternity hospital, mother's name, and ID number. Parents need to upload data and information about children at each stage of the disease in time to record the personal health information of the newborns, who would be followed up for at least 1 year. The complete and detailed health records are useful in the disease management of newborns and serve as a valuable system for parents for the early prevention, timely diagnosis, and prognosis of NCHD.

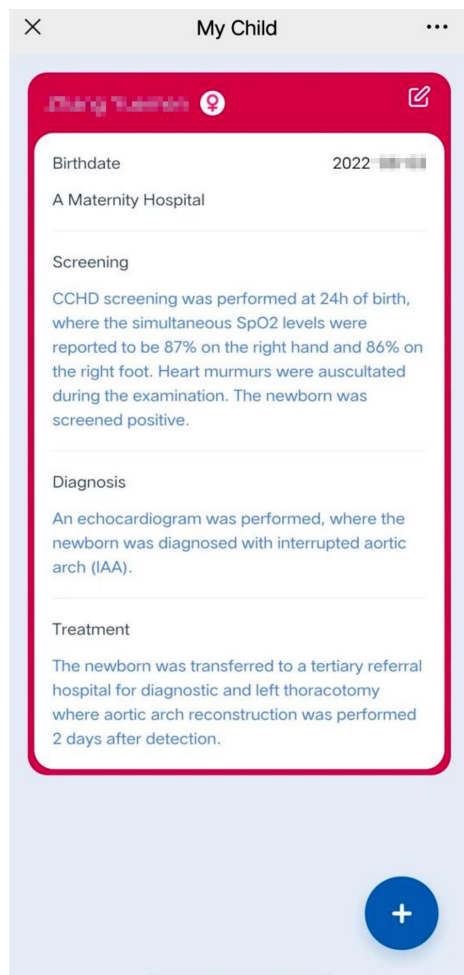


Figure 4 Human-machine interface on parent client-server.

Back-end data management and follow-up in medical staff client-server

The medical staff checked the registration information of newborns daily using the back-end data management system to ensure the registration of the information. The homepage of medical staff client-server is shown in *Figure 5*. The system will also send reminders of information entry, disease review, and follow-up. The staff also regularly verifies the back-end data, tracks the health status, and checks the perfection of the patient's health file, ensuring that each patient will be followed up on time and the effect of prognosis is recorded.

Reliable data on NCHD screening, diagnosis, treatment, and follow-up are accessible from the information management platform. The researchers can summarize dynamically and analyze the incidence, surgery, cure, and

survival rates of NCHD and accurately address the false negative rate of NCHD screening. This approach would help to evaluate and control the quality of NCHD screening programs regularly.

Application of message reminder

The message reminder has several functions: (I) inform parents to register and regularly fill in the test results in a timely manner; (II) recommend nearby hospitals and provide appointment reminders based on big data technology; (III) provide the parents with health information for improving their compliance with CHD management, including pathogenic factors of NCHD, CHD screening, potential therapeutic method, and the necessity of regular, timely follow-ups. *Figure 6* shows the user interface for managing message reminder functionality.

Whole-course management of NCHD

Based on the characteristics of each course of NCHD and the key points that deserve the attention of parents and medical staff, this intelligent management platform combines information technology and clinical specialization background to design a set of intelligent and specialized management processes for the whole-course management of CHD, providing technical support for the early detection, diagnosis, and treatment of NCHD.

Parent registration

The medical staff will introduce the functions of the management platform to the parents on site and guarantee the confidentiality of the information of newborns and parents. It will not be used for commercial purposes and parents will accept the medical services provided by the management platform voluntarily. Once parents have completed the registration and filled in their child's information, medical staff can check the personal details on the client-server system (*Figure 7*).

Screening phase

After the newborns are included in the system, the parents would be informed about the necessity of NCHD screening to avoid missing and improve compliance with the screening. The screening results, including the value of oxygen saturation, the result of heart murmur auscultation, and the judgment of the result (positive or negative screening), should be filled in and uploaded by parents after

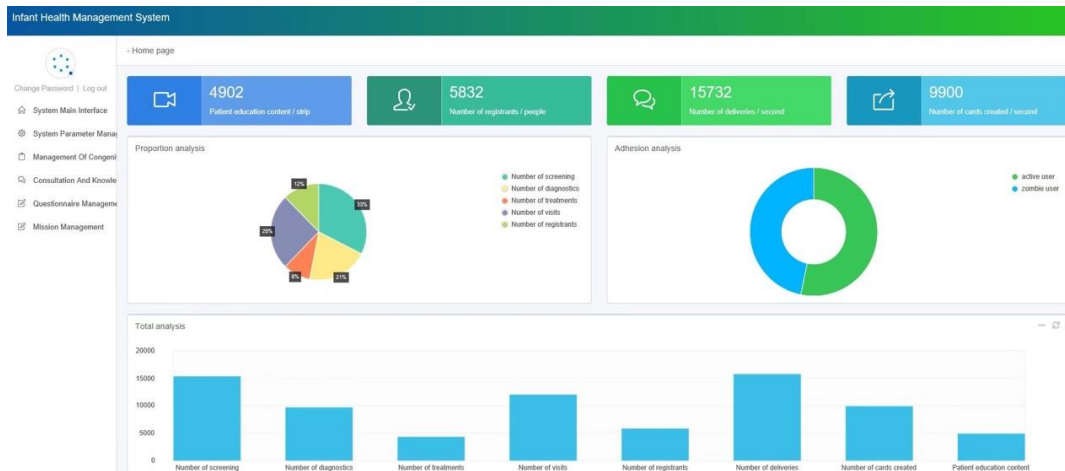


Figure 5 Homepage of medical staff client-server.

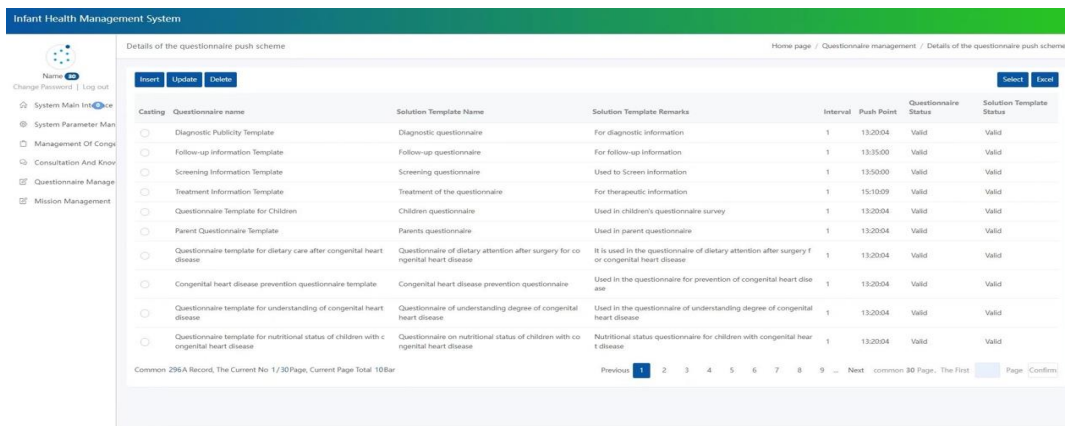


Figure 6 Management of message reminder.

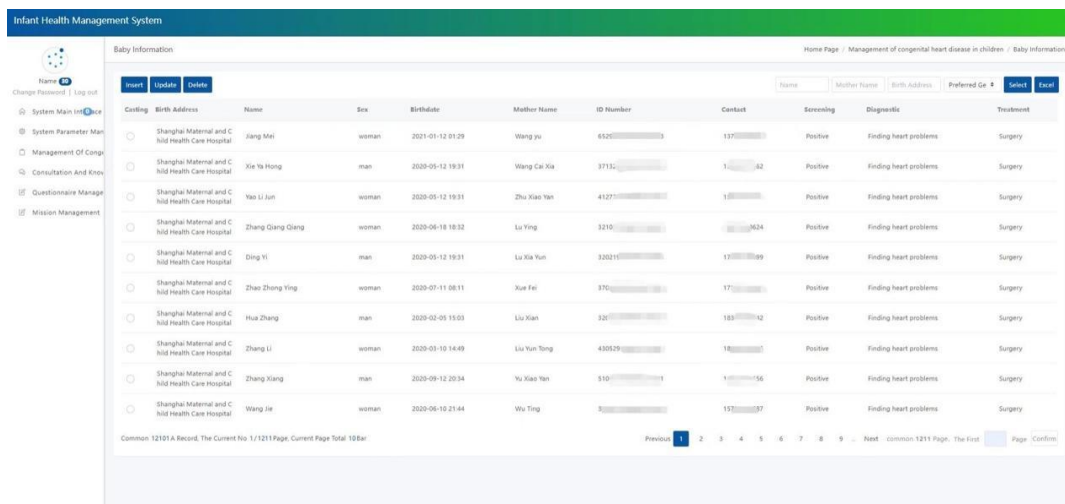


Figure 7 Personal information system interface for newborns on the medical staff client-server.

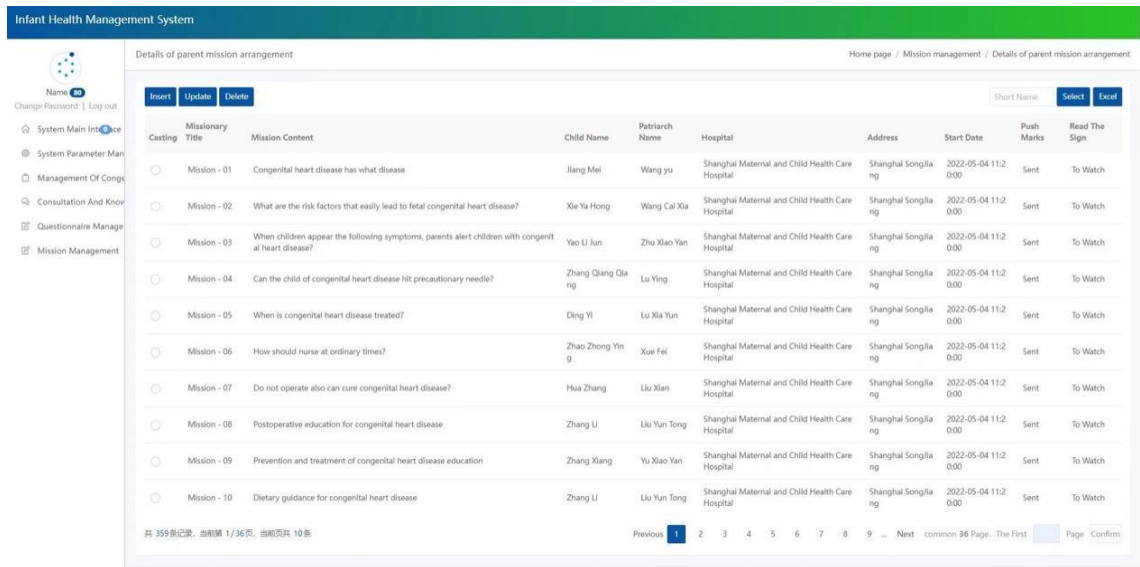


Figure 8 Parental task management interface on the medical staff client-server.

the maternity hospital has completed the screening.

Children with negative screenings automatically enter the follow-up process at 1 month, 3 months, 6 months, 9 months, and 12 months, and annually thereafter (parents can choose the date to automatically calculate the age). At these time points, the system automatically reminds the parents to enter the system to fill in whether symptoms related to suspected CHD are detected in their newborns after discharge from the hospital. Each time when the parent enters the system to fill in the follow-up results, it will automatically display the content (scientific knowledge of caring for babies at a specific month's age) that needs the parents' attention. At any time point where CHD is detected, the disease management pathway is entered for a positive screening result.

Diagnosis phase

First positive screening of newborns should complete the diagnosis within a week. Thus, parents are required to get their positive screening of newborns tested under cardiac ultrasound to confirm the disease, especially through message reminders automatically, and upload the results of the diagnosis. If the diagnosis results do not show any CHD, the disease management pathway for a negative screening result is entered.

Treatment phase

After treatment, the patient enters the follow-up pathway,

where medical staff will continue to follow up with the patient. The date, place, and method of received treatment should be imported into the platform. In this phase, relevant knowledge about disease management and daily care is also available.

The platform will send message reminders and educational content to parents at the screening, diagnosis, and treatment phases, informing them about the importance of timely diagnosis and providing relevant information about CHD. *Figure 8* displays the parental task management interface, allowing monitoring of whether parents have viewed the push notifications. In cases where the information remains unviewed, repeated reminders can be initiated.

Suggestions for improvement

The collected suggestions were as follows:

- (I) Inclusion of neonatal cases: the time for inclusion should be earlier but not later than delivery, specifically during the prenatal examination. It achieves early management and improves the efficiency and quality of diagnosis and follow-up of NCHD.
- (II) Synchronized data management between maternity hospitals and pediatric hospitals: the sharing and exchange of patient clinical information are essential for the functions of consultation, referral

Table 1 Spectrum of CHD diagnosed by echocardiography

Predominant defect	Number
PFO + PDA + PS	1
PDA	1
VSD + PFO + PDA	1
VSD + PFO	2
ASD + PDA	6
PFO	12
PDA + PFO	19
Total	42

CHD, congenital heart disease; PFO, patent foramen ovale; PDA, patent ductus arteriosus; PS, pulmonary stenosis; VSD, ventricular septal defect; ASD, atrial septal defect.

recommendation, and common recognition of test results. Thus, data management should focus on effective data locking.

- (III) Health management for parents: Parents' access to health information is increasingly diverse, but reliable health information could be identified. Knowledge of CHD should be conceived in simple language.

Medical staff have great expectations and have given affirmation to this information platform in the management of NCHD and the resulting social benefits. The interview provided the parents with a high-quality method to acquire disease-related knowledge.

Initial usage characteristics

We successfully enrolled a total of 891 infants in the two settings from June 1, 2023, to August 31, 2023. Out of these infants, 95.06% tested negative, whereas 4.93% tested positive. Echocardiography was performed within 7 days after birth for all babies who were classified as test positive. *Table 1* shows that a total of 42 cases of CHD were detected. Two infants were diagnosed with mild pulmonary hypertension and no obvious abnormalities, respectively. We will persist in monitoring these diagnosed cases via the platform, send reminders to parents to schedule regular check-ups or treatment for their children, and disseminate pertinent disease-related scientific information to alleviate parents' stress, enhance their understanding of CHD, and improve their ability to care for their children. We will persist in monitoring the diagnosed cases via the platform,

send reminder messages to parents to guarantee their children attend check-ups or receive treatment on a regular basis, and disseminate pertinent disease-related scientific knowledge to alleviate parents' stress.

Discussion

This is the first study to establish a big data management platform for NCHD screening, diagnosis, treatment, and follow-up, incorporated into the self-reporting and management of parents. We discussed the present issues with NCHD implementation, monitoring, and M-Health APPs based on big data technology. The detailed architecture and workflow of the platform are also presented.

Involving parents in managing CHD on this platform has several advantages. Not only does it help change their health behaviors and increase their understanding of the condition, but also provides a follow-up mechanism for newborns with negative screenings. This enables parents to be more vigilant about their children's well-being in their daily lives. If any newborns show symptoms of CHD, parents can seek medical attention promptly for a timely diagnosis, thereby reducing the mortality rate of CHD in newborns and infants. Additionally, this not only improves the quality of life for affected children but also has a positive impact on the overall health of the family. Conversely, for newborns with positive screenings, the platform can track and monitor their cardiac ultrasound. The results should serve as a reminder to parents to schedule timely rechecks, which will in turn enhance the chances of positive cardiac ultrasound screenings.

After obtaining all the CHD records from the platform, we can delve into the risk factors associated with the disease. Research indicates that several risk factors, such as maternal exposure to air pollutants (SO₂, NO₂, PM10, and PM2.5) (52), daily temperatures exceeding 30 °C (53), and limited access to green spaces (54) that are often associated with lower household income, can heighten the risk of CHDs. Further studies are warranted to validate these findings by analyzing the valuable data from our platform and other pertinent information from external databases.

It is crucial to maintain close communication with the technical team and users (the parents) throughout the development and use of the platform. To guarantee the usability of the platform, it is imperative to swiftly communicate user requirements to the technical team and implement necessary modifications to features or interfaces. Our goal is to offer prompt responses to parents' queries, consistently improve the user experience, and fulfill user

requirements. It is crucial for medical staff to effectively track the condition of newborns by encouraging parents to consistently use the platform and report their condition regularly. The challenge of limited parental stickiness on the platform will be significant. To motivate data self-reporting, we will prioritize platform promotion in the initial stages, alongside offering medical consultation services, updating scientific knowledge on the platform, and emphasizing the need for monitoring potential conditions. Another issue arises due to parents having to report information individually, which is the accuracy of the data. In light of this fact, we strongly encourage parents to capture a photo of their exam results and upload it onto the platform.

In the complex context of the healthcare system, the implementation of an intelligent platform for NCHD management holds significant benefits, including improved efficiency, data-driven insights, and remote healthcare delivery. However, several challenges must be addressed, such as data security and privacy, integration with existing healthcare systems, regulatory compliance, and varying levels of technological infrastructure across regions. To maximize its benefits, a tailored approach is required, acknowledging that one-size-fits-all strategies may not be effective. Strategies should include robust data encryption, collaboration with regulatory authorities, and pilot programs. public awareness initiatives, infrastructure investment, and continuous improvement efforts. To effectively navigate the intricate healthcare system in China and unlock the full potential of intelligent platforms for improved management of NCHD, it is imperative to implement these measures.

Conclusions

This article reviewed the challenges to the implementation and surveillance of NCHD as well as the applications of M-Health based on big data technology. This is the first big data management platform for NCHD, involving the whole-course management of CHD screening, diagnosis, treatment, and follow-up. It is incorporated into the parental self-report and management with big data mining, the characteristics of humanization, intelligence, and integration to meet the actual needs of the patients, families, and clinical practice and achieve the expected design effect. Also, the detailed architecture and workflow of the platform are provided. It is crucial to remain vigilant about technical and security concerns while using the platform. Timely feedback and adjustments should be provided to address any

identified issues.

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Footnote

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Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study was approved by the Research Ethics Committee of the Children's Hospital of Fudan University, Shanghai, China ([2021]141). All parents of participants used this platform voluntarily and provided informed consent.

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