



OHDSI
OBSERVATIONAL HEALTH DATA SCIENCES AND INFORMATICS



소아암·희귀질환지원사업단
CHILD CANCER & RARE DISEASE PROJECT



공동연구사업부
소아암·희귀질환지원사업단

Connecting pediatric data for better child health

KIDSNet

Korea Kids Network

Suhyun Kim

Healthcare AI Research Institution (HARI),
Seoul National University Hospital (SNUH)



Seoul National University Hospital



Number of Employees (2025.12.31)

Classification	Number
Doctors	1,559
Nurses	3,188
Pharmacists	150
Medical Technologists	936
Others	2,688
Total	8,521

Inpatient beds (2025.12.31)

Classification	Main	Children	Cancer	Total
General beds	1,130	260	46	1,436
Special care beds	23	6	-	29
I.C.U	106	24	-	130
N.I.C.U	-	40	-	40
Total	1,259	330	46	1,635



Seoul National University Hospital

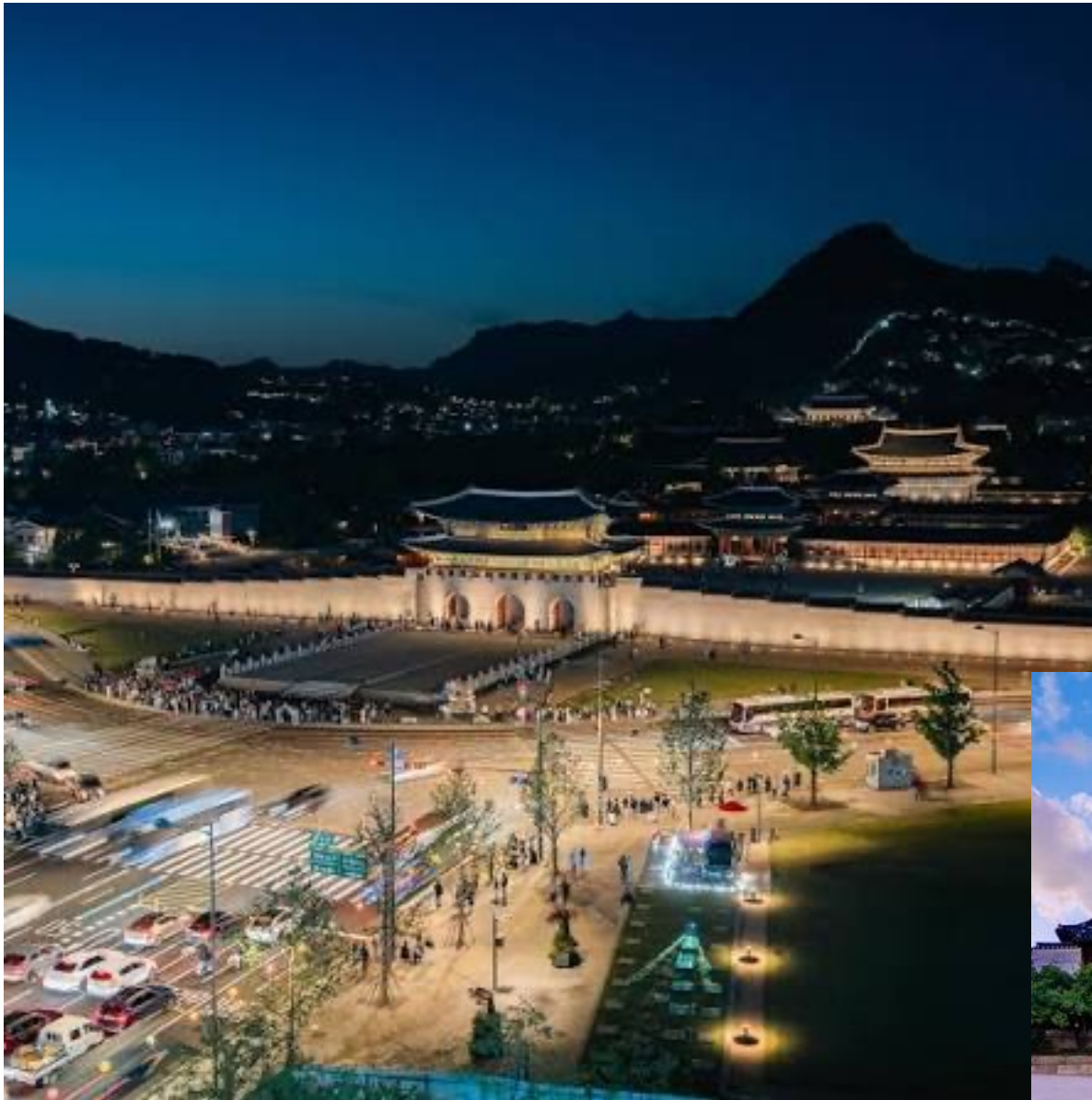
2026
OHDSI APAC
Symposium



Han River



Gang Nam
江南





Child Cancer & Rare Disease Project

The management philosophy
of the late Chairman Lee Kun-hee

"Respect for Humanity, Contribution to Society"

KRW 1 Trillion Donated to Korea's Healthcare Sector

Infectious Disease Response

Establishment of a specialized infectious
disease hospital and research institute



USD 750M

Support for Children with Pediatric Cancer & Rare Diseases

Led by Seoul National
University Children's Hospital



USD 300M

Overcoming Pediatric Cancer & Rare Diseases Initiative

SAMSUNG

SNUH 

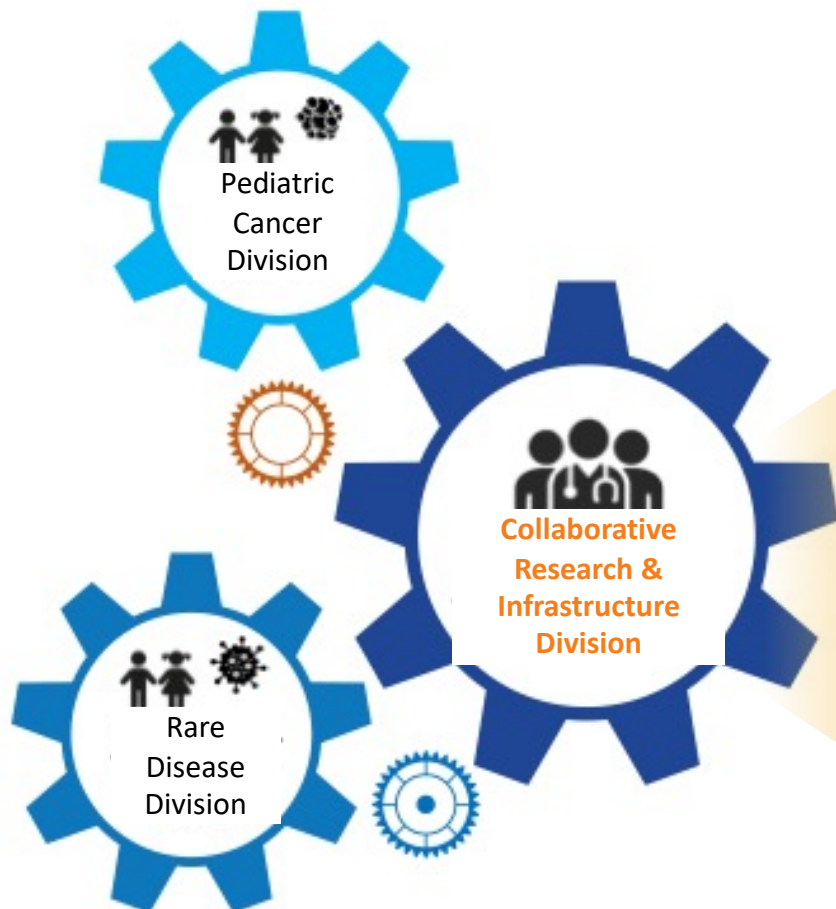
The family of the late Chairman Lee Kun-hee
&
Seoul National University Hospital

- Jan 2021 — Donation proposed by the Samsung family
- Mar 2021 — Master plan for the "Overcoming Pediatric Cancer & Rare Diseases" initiative established
- May 3, 2021 — Donation agreement ceremony held





Essential Elements of Pediatric Healthcare



Conducting Innovative Clinical Research

- Focused research on pediatric cancer and rare diseases
- Strengthened research capacity for severe pediatric conditions, driving improvements in care quality
- Shifting from treatment-centered care to big data-driven patient management solutions

Accurate Diagnosis and Safe Treatment

- Building an integrated genomic and clinical bio-big data platform
- Expanding opportunities to pursue **"a happy life for every child"**



Benchmarking PEDSnet

home / about / history

History

PEDSnet is a large, national community of hospitals and healthcare organizations, researchers and clinicians, and patients and families. This community works together to identify the most important research questions that can reduce children's suffering and support their healthy development. When we do research, our goal is to conduct it as inexpensively and quickly as possible, while engaging all of our stakeholders in the research process along the way.

PEDSnet is a multi-specialty network that conducts observational research and clinical trials across multiple children's hospital health systems. We are governed by parents and senior leaders in these health systems. PEDSnet has produced reusable and expandable governance, logistical, informatics, regulatory, scientific, and training resources, organized as a Pediatric Research Commons. PEDSnet has created a longitudinal data resource that dates back to 2009, cutting across all pediatric diseases, and including all pediatric specialties.

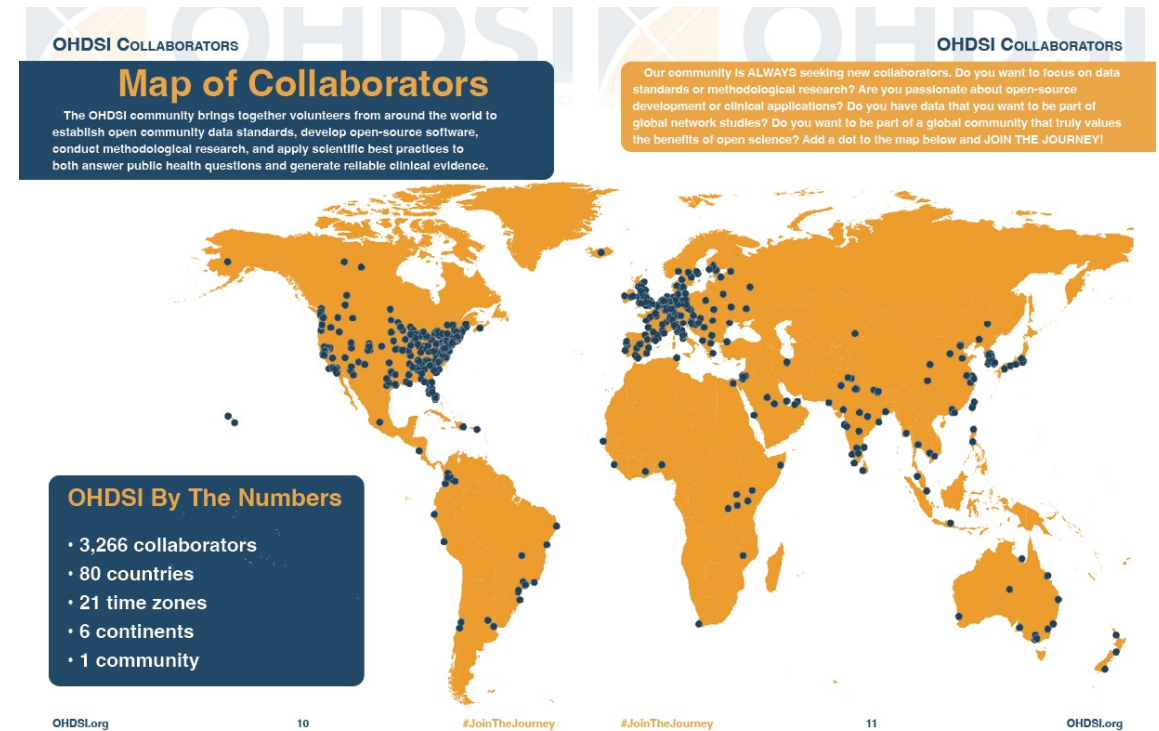
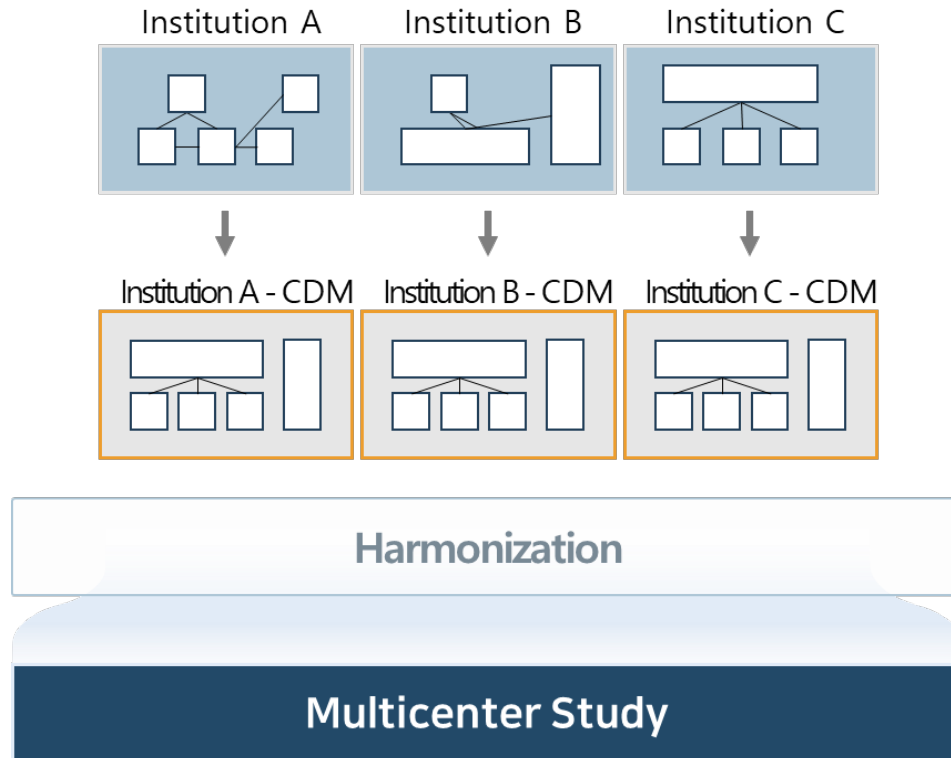
Domain	Examples	Utility to research
Demographics	Age, date of birth, gestational age, sex, ethnicity, race, zip code, PEDSnet health system site, primary care provider(PCP), death and cause of death(if available), tobacco use	Exposures, health determinants, confounders, mediators, effect modifiers, outcomes (death); Zip codes and health system site can be geo coded and linked to area-level environmental factors influencing health and health outcomes;
Outpatient encounters (~75 visit specialty types)	Primary care visits, specialty care clinics (e.g., cardiology, endocrinology, nephrology, oncology, etc), physical therapy, occupational therapy, speech language pathology, medical genetics/genomics, etc	Provides longitudinal follow-up and duration of clinical course; health care utilization measures; Distinguishes between specialty care (and type of specialty care) and primary care visits;
Inpatient admissions	Length of stay, discharge status; diagnoses, procedures, medications, and lab results associated with inpatient stay	Measures health care utilization for patients and conditions; Provides longitudinal data to evaluate disease course and severity of illness;
Emergency department encounters	Diagnoses, procedures, medications, and lab results associated with ED visit; ED visits resulting in inpatient admission	Provides markers for disease progression and clinical outcomes; Health care utilization measures; Markers for chronic disease control and severity;
Anthropometrics	Height (cm) and weight (kg), BMI, head circumference	Outcomes, health determinants, confounders, mediators, effect modifiers; Markers for health status;

Vital signs	Temperature, blood pressure
Providers	Specialty, health care facility
Diagnosis	Final diagnoses are recorded at each encounter and are mapped to a standardized codes (typically SNOMED-CT)
Procedures	Procedures are recorded at each encounter and are mapped to standardized SNOMED-CT, ICD-9 Procedure, ICD-10 Procedure, CPT-4, and HCPCS codes
Prescribed medications	Medications ordered are recorded at each encounter and mapped to a standardized RxNorm code
Dispensed Medications	Medications dispensed, when available, are recorded and mapped to a standardized RxNorm code
Laboratory Results	Key components of lipid panel, complete metabolic panel, complete blood counts, microbiologic cultures, liver function tests, urinalysis, viral panels, etc

PEDSnet(<https://pedsnet.org/>)



Adopting OMOP CDM: Enabling Multicenter Research





KIDSNet (Korea Kids Network)



We built a collaborative research network for child cancer & rare diseases

A CDM established across children's hospitals nationwide — improving research accessibility through multimodal data

7

hospitals

1.69M

pediatric patients

5-yr

2022 –

OMOP

CDM standardized



Growing the Network: Five Years of Phased Institutional Expansion



Year 5 (2026)



CNUH

joins as a collaborating
institution

Year 4 (2025)



CNUH

joins as a collaborating
institution

Year 3 (2024)



KNUH

joins as a collaborating
institution

Year 2 (2023)



JNUH

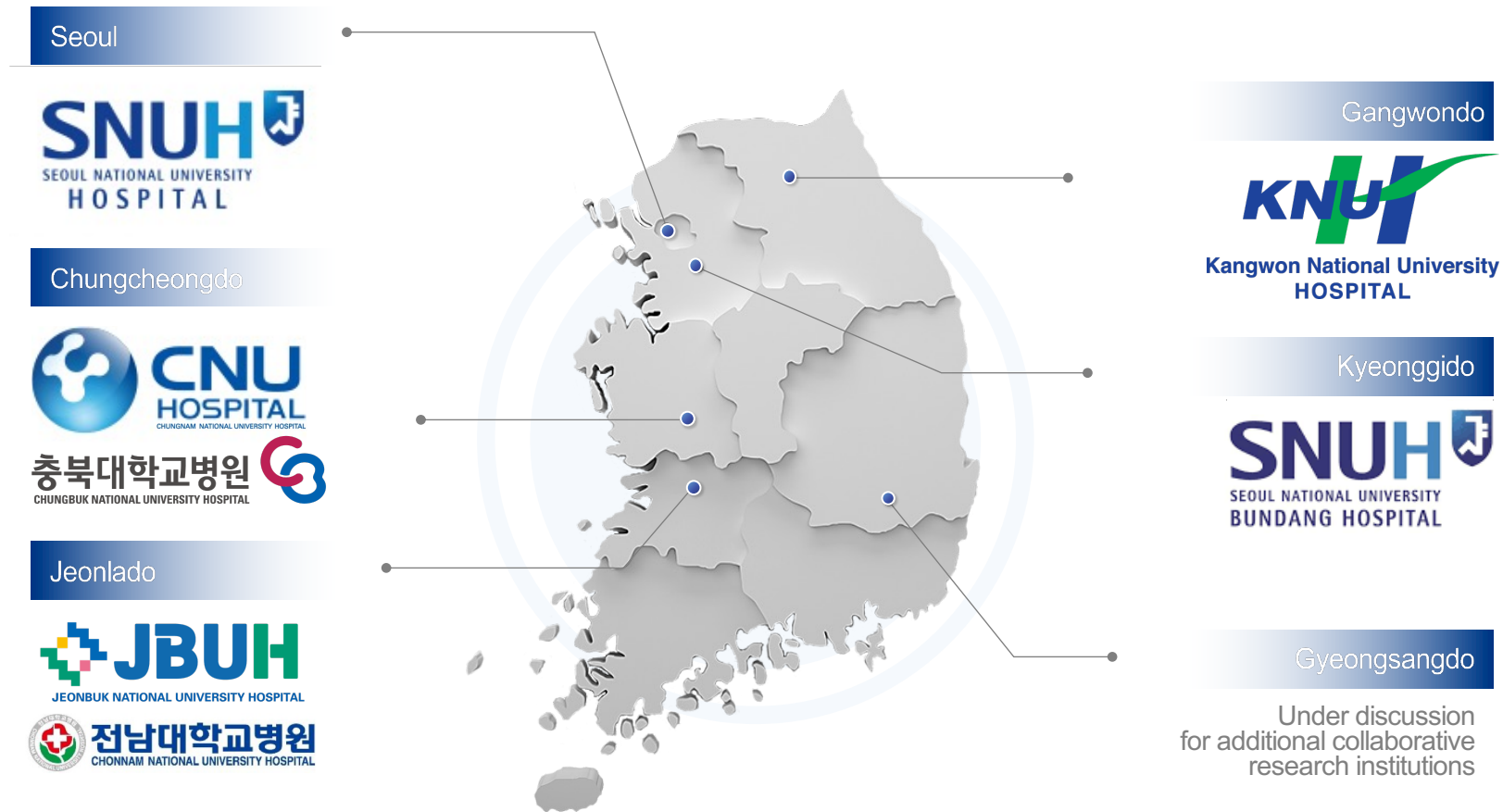
joins as a collaborating
institution

Year 1 (2022)





Data Network of 7 Hospitals, 1.69M Pediatric patients





Pediatric-Specific CDM Data Status

Institution		Pediatric CDM Database		2026 Incremental Build		
		Data Period	Patients Count	Data Period		Patients Count
Lead	Seoul National University Hospital	2004.10 - 2025.12	824,077	+12 months	2025.01 - 2025.12	35,929
Sub 1	Seoul National University Bundang Hospital	2003.05 - 2024.12	508,225	Incremental build scheduled for H2		
Sub 2	Chungnam National University Hospital	2019.11 - 2026.04	118,843	+ 7 months	2025.10 - 2026.04	20,514
Sub 3	Jeonbuk National University Hospital	2010.01 - 2025.12	177,898	+ 12 months	2025.01 - 2025.12	19,205
Sub 4	Kangwon National University Hospital	2003.08 - 2026.03	136,125	Incremental build scheduled for H2		
Sub 5	Chungbuk National University Hospital	2020.07 - 2025.06	344,718	+ 6 months	2025.01 - 2025.06	296,819
Sub 6	Chonnam National University Hospital	2011.01.~2025.12	193,173	New build	2011.01 - 2025.12	193,173

※ Pediatric: aged 18 years or younger at first visit, As of June 2026



Built from what pediatric clinicians asked for

Perinatal

- Nursing admission records
- Maternal pregnancy & delivery history
- Infection status (HBV · syphilis · HIV)
- ventilator settings

Neonatology

Growth & body composition

- Height · weight · head circumference
- + age-based percentiles
Body composition (BCM · BIA)

Endocrinology, Nephrology

Special tests

- Cardiac & brain ultrasound
- Pulmonary function · allergy testing

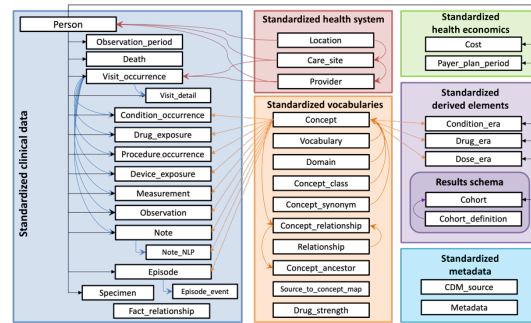
Exists only as free-text reports,
no structured codes

Cardiology, Neurology,
Gastroenterology, Pulmonology,
Allergy

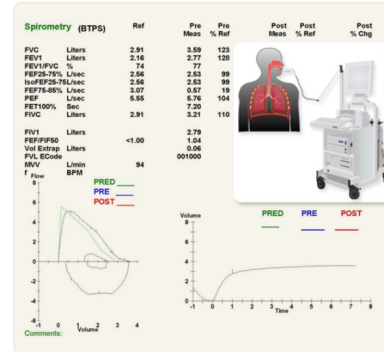


CDM Construction for Pediatric-Specific Data

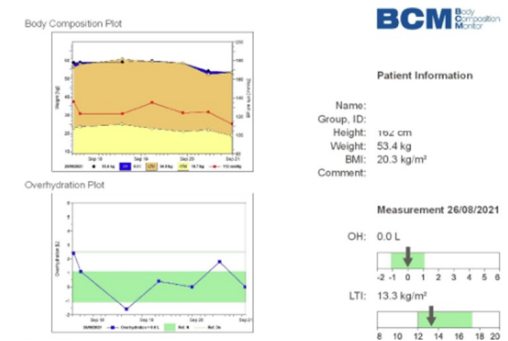
Clinical Data



Pulmonary Function Test (PFT)



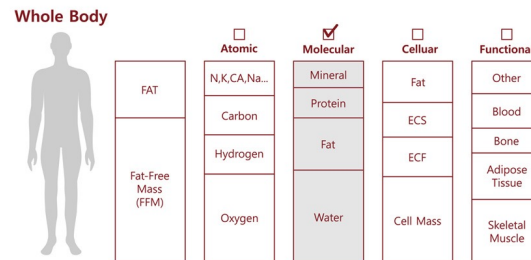
Body Composition Monitor (BCM)



Allergy Testing (MAST · SPT)



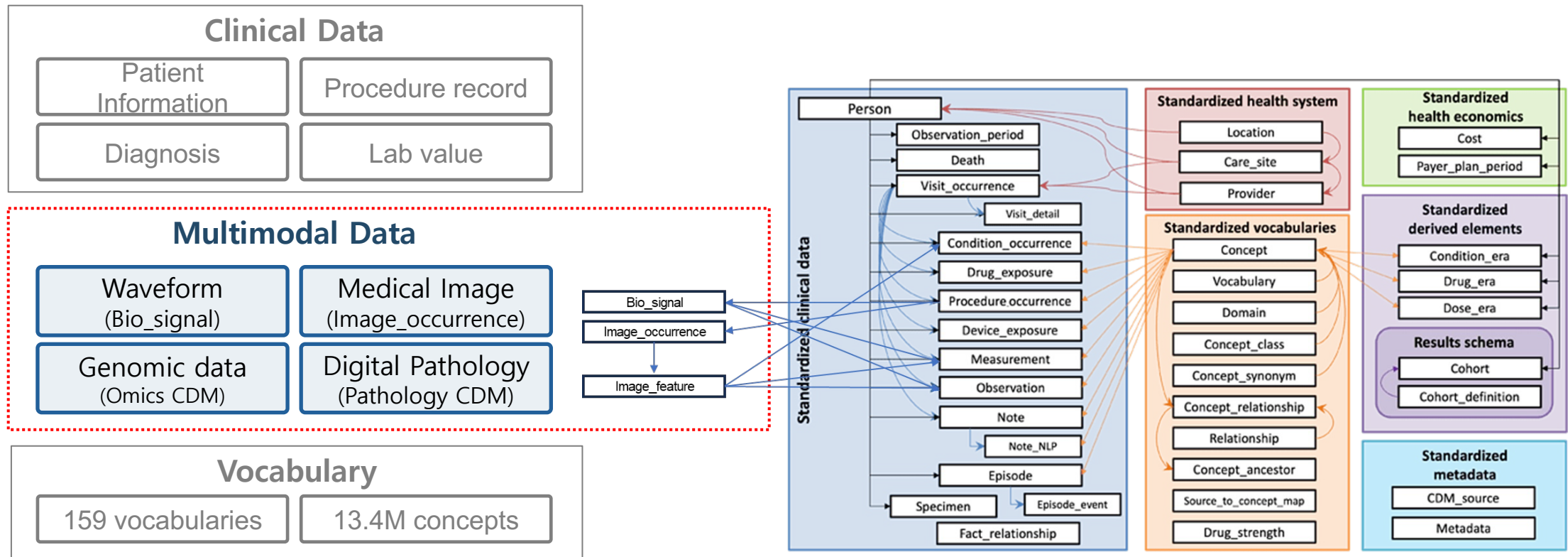
Body Composition Analysis



NICU Discharge Summary



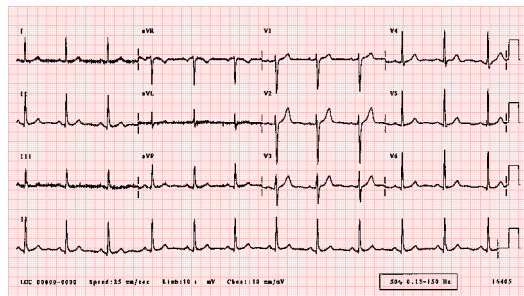
CDM Extension



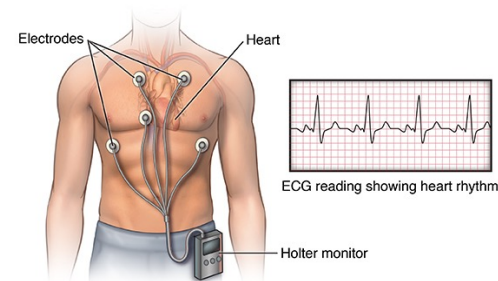


CDM Extension Construction for Pediatric-Specific Data

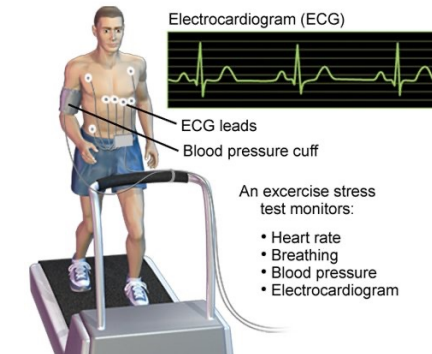
12-lead ECG



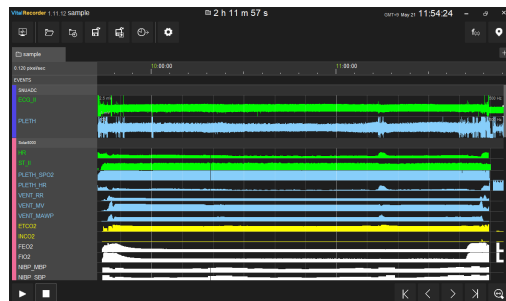
24hour ECG, Holter



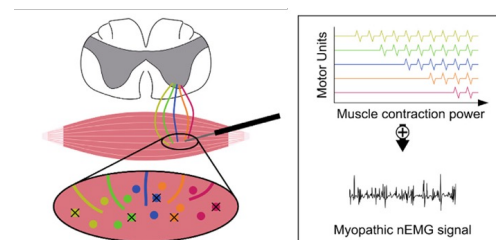
Treadmill ECG



Vital monitoring record



Electromyography (EMG)



Medical Image





Proposing a Bio-signal Extension Domain

A common schema to capture bio-signals — ECG, Holter, TMT, ABR, EMG, Vital record and beyond

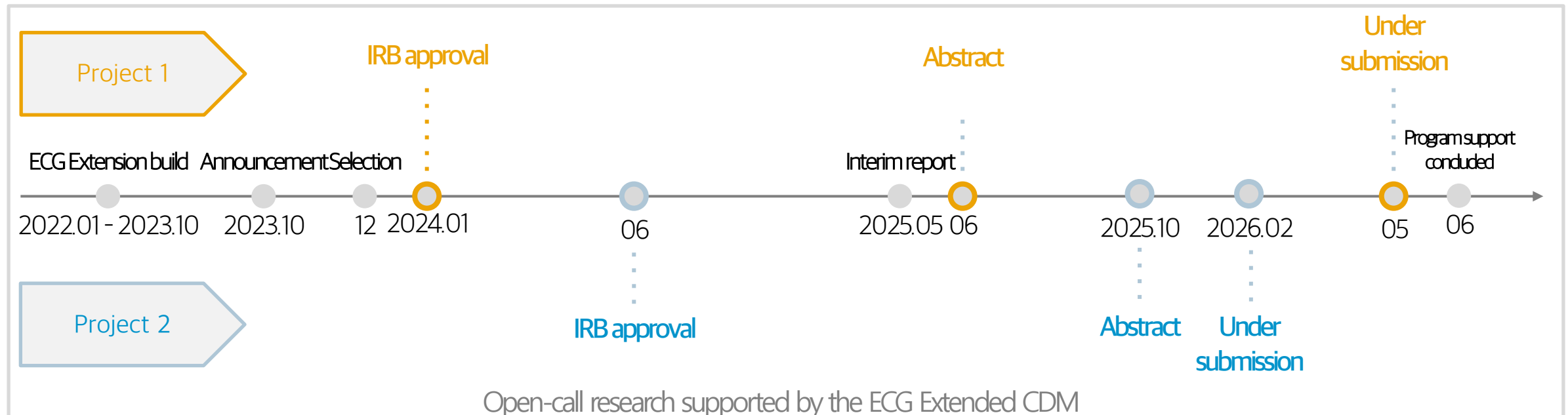
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1	bio_signal_id	Yes	No	Yes	integer		1
2	person_id	No	Yes	Yes	integer		1209972
3	bio_signal_concept_id	No	Yes	Yes		Bio signal concept id	4179815
4	bio_signal_source_value	No	No	No	varchar(200)		EMG - Sensory NCS L Median Digit II
5	bio_signal_date	No	No	No	date	Date	2015-01-14
6	bio_signal_datetime	No	No	No	timestamp	Date and time	2015-01-14 09:21:36
7	file_path	No	No	Yes	varchar(200)	File path	1209972_20150114_0921.xml
8	visit_occurrence_id	No	Yes	No	integer		48746453
9	event_id	No	Yes	No	procedure		12345
11	evnet_field_concept_id	No	Yes	No	procedure		1147301



Open-Call Research (ECG)

2023 — Full-cycle research support and successful completion of the first open-call studies using ECG Extended CDM data

- Project 1 (PI: Prof. Mikyoung Song, SNUH)
Deep learning-based ECG model to predict biventricular dysfunction and cardiac dilation in congenital heart disease
- Project 2 (PI: Prof. Jihye You, JNUH)
12-lead ECG model for early detection of mildly reduced left-ventricular function in neonates





Open-Call Research (ECG project 1)

Multimodal Deep Learning for Predicting Ventricular Dysfunction in Congenital Heart Disease Patients Using ECG and Metadata

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Introduction

1. Clinical Background & Research Gap

- 선천성 심장병(CHD)은 해부학적 구조가 다양하고 복잡하여, 장기 추적 중 심실 기능 저하, 확장, 심근 섬유화 등 이차적 합병증이 자주 발생함
- 이러한 심기능 이상은 심부전, 제1심, 조기사망 등의 중대한 임상 결과로 이어질 수 있어 조기 예측 및 모니터링이 중요함
- 그러나 CHD 환자는 구조적 이질성과 데이터의 희소성으로 인해 ECG 기반 심기능 예측 연구가 거의 수행되지 않았음

2. Role of ECG and Study Objective

- ECG는 비침습적이며 비용이 낮고 반복 측정이 가능하여 심기능 이상을 반영할 수 있는 유용한 진단 도구임
- 본 연구는 CHD 환자에서 ECG 신호와 임상 데이터를 결합한 멀티모달 딥러닝 모델을 개발하고자 함
- 심장 MRI 기반의 심실 기능 레이블과 ECG를 연계하여, CHD 환자의 심기능 이상을 조기에 예측할 수 있는 인공지능 기반 예측 도구 구축을 목표로 함

Methods

1. Study Population & Data Collection

- 2003년부터 2023년까지 서울대학교병원에서 선천성 심장병(CHD)으로 진단받고 심장 MRI를 시행한 1,565명의 환자를 초기 코호트로 포함함
- MRI에 우심실 박출물(RV EF) 정보가 없거나 단심실 구조, systemic RV, 심근병증이 있는 경우, 또는 MRI 시점 전후 6개월 내 ECG가 없는 경우는 제외함
- 최종적으로 1,057명의 환자와 1,680건의 MRI-ECG 매칭 데이터를 분석에 포함함

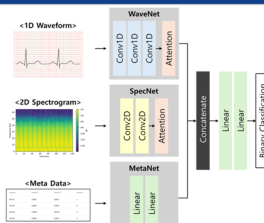


Figure 1. Architecture of the Proposed Multimodal ECG Model

2. Model Development & Evaluation

- 입력은 12-lead ECG waveform(8개 리드 기반 파형)과 메타데이터(age, sex, BSA, QRS duration)로 구성되며, 출력은 5개의 심실 기능 이상 여부를 예측함
- 모델은 세 가지 모듈로 구성됨: 1D ECG waveform을 처리하는 1DCNN 모듈 (WaveNet), ECG에서 생성된 스펙트로그램을 입력으로 받아 학습하는 2D CNN 모듈 (SpecNet), 나이, 성별 등 메타데이터를 입력으로 하는 MLP 모듈 (MetaNet)
- 세 모듈의 출력을 결합하여 최종 예측을 수행하는 멀티모달 구조임

Results

Model Performance

- 멀티모달 딥러닝 모델은 중 5개의 심실 기능 이상 레이블에 대해 다중 이진 예측을 수행함
- 중증 우심실 기능 저하(RV EF ≤ 35%)에서 AUROC 0.8644로 가장 높은 분류 성능을 보임
- rv_combined_or(0.788)이 가장 높은 AUROC를 기록해, 불균형 상황에서 양성 성향 검출력이 우수함

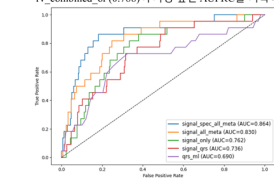


Figure 2. ROC Curves for RV Dysfunction_35

- 경도 이상 포함 우심실 기능 저하(RV EF ≤ 46%), 우심실 확장, 복합 우심실 이상에서도 AUROC 0.71 이상, F1-score 0.60-0.75 수준의 양호한 예측 성능을 보임

Table 1. Performance Metrics of the Multimodal ECG Model

Label	AUROC	AUPRC	Accuracy	Precision	Recall	F1
rv_dysfunction_35	0.8644	0.3284	0.8958	0.3415	0.6364	0.4444
rv_dysfunction_46	0.7114	0.6689	0.6577	0.6030	0.7692	0.6761
rv_dilatation	0.7328	0.6776	0.6607	0.5510	0.8060	0.6545
rv_combined_and	0.7655	0.5808	0.7232	0.4965	0.7609	0.6009
rv_combined_or	0.7253	0.7884	0.6458	0.6339	0.9444	0.7586

Discussion and Conclusion

- 본 연구는 선천성 심장병(CHD) 환자에서 ECG와 메타데이터를 활용한 멀티모달 딥러닝 모델을 통해 심실 기능 이상을 예측할 수 있음을 입증함
- 특히 우심실 기능 저하 및 확장에 대한 예측 성능이 우수하며, 임상적으로 조기 개입에 기여할 수 있는 가능성을 시사함
- ECG라는 간편하고 접근성 높은 데이터 기반의 AI 모델이 CHD 환자 관리에 실질적으로 활용될 수 있는 기반을 마련함

References

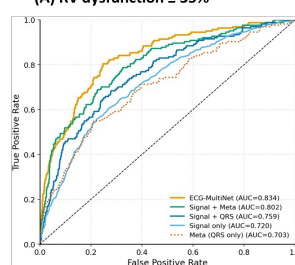
- [1] Sangha V, Nargesi AA, Dingra LS, et al. Detection of left ventricular systolic dysfunction from electrocardiographic images. *Circulation*. 2023;148(9):765-777.
- [2] Anita ZI, Kapa S, Lopez-Jimenez F, et al. Screening for cardiac contractile dysfunction using an artificial intelligence-enabled electrocardiogram. *Nat Med*. 2019;25(1):70-74.
- [3] Vaid A, Johnson KW, Boudley MA, et al. Using deep-learning algorithms to simultaneously identify right and left ventricular dysfunction from the electrocardiogram. *Cardiovascular Imaging*. 2022;15(3):393-410.
- [4] Ana Cristina Andrade et al. Determinants of Left Ventricular Dysfunction and Remodeling in Patients With Corrected Tetralogy of Fallot. *J Am Heart Assoc*. 2019 Sep 3;8(17):e009618.
- [5] Craig S Boudley et al. Prevalence of left ventricular systolic dysfunction in adults with repaired tetralogy of Fallot. *Am J Cardiol*. 2011 Apr 15;107(8):1215-20.

Contacts

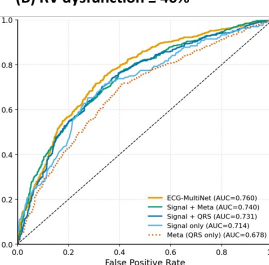
Gyunho Roh* (samsuno@snu.ac.kr) & Professor Kwangsoo Kim* (kksoo716@gmail.com)

Results – ML model performance

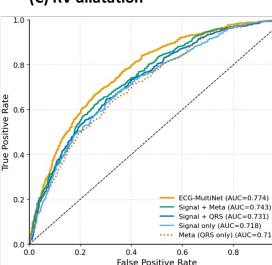
(A) RV dysfunction ≤ 35%



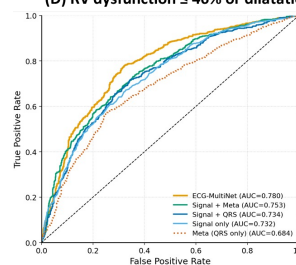
(B) RV dysfunction ≤ 46%



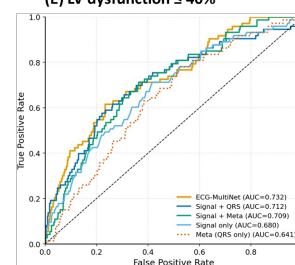
(C) RV dilatation



(D) RV dysfunction ≤ 46% or dilatation



(E) LV dysfunction ≤ 40%



Open-Call Research (ECG project 2)

Detection of Reduced Left Ventricular Ejection Fraction in Neonates

Using a Deep Learning Model Based on 12-Lead ECGs

Jihye You¹, Jiwon Kim², Hee-Soo Kim³, Kwangsoo Kim⁴, Hyun Ho Kim¹

¹Department of Pediatrics, Jeonbuk National University Hospital, ²Interdisciplinary Program in Medical Informatics, Seoul National University, ³Department of Anesthesiology and Pain Medicine, Seoul National University Hospital ⁴Department of Transdisciplinary Medicine, Seoul National University Hospital

The Korean Society of Cardiology

COI Disclosure

Name of First Author: Jihye You, Jiwon Kim

The authors have no financial conflicts of interest to disclose concerning the presentation

Background

- Diagnosing neonatal LVEF is challenging
- Echocardiography: gold standard but resource-intensive
- Need for simple, scalable ECG-based screening

Objectives

- To develop a deep learning model that predicts reduced LVEF ($\leq 55\%$) in neonates using standard, readily available 12-lead ECGs.
- The goal is to create a rapid, non-invasive screening tool for the early risk stratification of this vulnerable population.

Method

Study design and population

- Design: Single-center retrospective cohort study
- Population: Neonates (<1 month) underwent ECG (2004-2022)
- Exclusion criteria: 1) No echocardiographic data (n=1,038)
2) >7 days between echo and ECG (n=719)
3) Missing LVEF values (n=593)

Final cohort: 2,078 patients;

Control (LVEF >55%): n=1,880; Reduced LVEF ($\leq 55\%$): n=198

Data preprocessing and model training

- ECG input: 12 leads (I, II, III, V1-V6, aVR, aVL, aVF); 10-sec segments (500 Hz)
- Data split: Training set (before 2020): n= 1,856; Test set (2020 onward): n= 222
- Model architecture: CNN-based ResNet (Figure 1)
- Training strategy:
 - Train : validation = 89 : 11 (train: 1,646; validation: 210)
 - 20 epochs; early stopping after 3 epochs without AUPRC improvement

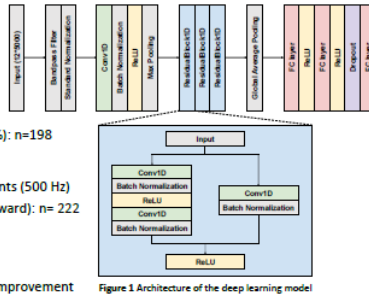


Figure 1 Architecture of the deep learning model

Result

- Hyperparameters:
 - Learning rate = $7e-5$
 - Batch size = 32
 - Dropout = 0.1
- Dataset: 2,078 samples (class imbalance $\approx 10:1$)

Subgroup	Accuracy	F1-score	AUROC	AUPRC	Sensitivity	Specificity
All	0.86	0.24	0.83	0.31	0.50	0.87
CHD						
True	0.85	0.22	0.81	0.32	0.44	0.87
False	0.87	0.40	0.95	0.50	1.00	0.86

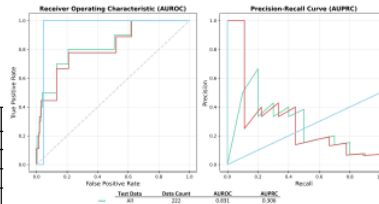


Figure 2 AUROC & AUPRC for all test data

Conclusion

- Developed a CNN-based ECG model predicting reduced LVEF ($\leq 55\%$) in neonates
- Achieved high performance (AUROC 0.87, AUPRC 0.82) despite small, imbalanced dataset
- ECG-based AI offers a rapid, non-invasive tool for early cardiac risk screening in neonates

2025.10.16(Thu.)-18(Sat.)

Grand Walkerhill, Seoul, Korea





Open-Call Research (NICU Discharge Record)

NICU Discharge Record: Data Collection & Standardization (2022–2024)

입원사유 및 병력요약

Maternal history

■ Mother's name

■ Mother's Hosp. No.

■ Age

■ Para

■ 교육 정도

모: ☐ 초졸 ☐ 중졸 ☐ 고졸 ☐ 대졸 이상 ☐ 모름

부: ☐ 초졸 ☐ 중졸 ☐ 고졸 ☐ 대졸 이상 ☐ 모름

■ 출신 국가

모: ☐ 대한민국 ☐ 중국 ☐ 일본 ☐ 미국 ☐ 기타 ☐ 모름

부: ☐ 대한민국 ☐ 중국 ☐ 일본 ☐ 미국 ☐ 기타 ☐ 모름

■ 결혼 상태

☐ 결혼 ☐ 이혼 ☐ 미혼 ☐ 미혼 동거

■ PROM

☐ unknown ☐ no ☒ yes

■ Placental Biopsy

A ☐

CD ☐

U ☐

C ☐

■ Amniotic fluid

☐ unknown ☐ oligohydramnios (AFI<5) ☐ polyhydramnios (AFI>24) ☐ normal

■ DM

☐ no ☐ GDM ☐ overt DM ☐ unknown

■ HTN

☐ no ☐ PH ☐ chronic HTN ☐ unknown

■ Assisted Reproductive Technology

☐ no ☐ IVF-ET ☐ IUI ☐ others

■ Prenatal steroid

☐ no ☒ yes (본인 1주일 이내 투여가 완료된 경우)

■ 산전 항생제 사용 여부 (본인 72시간 이전부터 본인 전까지 기간 중 발생제 투여된 경우)

☐ 없음 ☐ 있음 ☐ 모름

■ Other maternal conditions

■ Perinatal History

■ Delivery Place

☐ inborn ☒ outborn ☐ others ☐ unknown

hospital name

D.O.B

D.O.A

■ GP

week days

■ EDC

date

■ Birth weight

g, percentile

☐ SGA ☐ AGA ☐ LGA

■ Length

cm, percentile

■ Head circumference

cm, percentile

Sample NICU discharge record (original)

Observation_ concept_id	concept_name	domain	vocabulary	Qualifier_ concept_id	concept_name	domain	vocabulary	Value_as_ concept_id	concept_name	domain	vocabulary
44789950	Gestational age	Observation	SNOMED								
4059478	Estimated date of delivery	Observation	SNOMED								
4264825	Birth weight	Measurement	SNOMED								
4116803	Birth weight centile	Measurement	SNOMED					4123497	<3	Meas Value	SNOMED
4116803	Birth weight centile	Measurement	SNOMED					신규생성(서울C 3-9	Meas Value		
4116803	Birth weight centile	Measurement	SNOMED					신규생성(서울C 10-49	Meas Value		
4116803	Birth weight centile	Measurement	SNOMED					신규생성(서울C 50-90	Meas Value		
4116803	Birth weight centile	Measurement	SNOMED					신규생성(서울C 91-97	Meas Value		
4116803	Birth weight centile	Measurement	SNOMED					4131980	>97	Meas Value	SNOMED
4264825	Birth weight	Measurement	SNOMED					4145947	Small for gestational age fetus	Condition	SNOMED
4264825	Birth weight	Measurement	SNOMED					4076643	Appropriate growth	Observation	SNOMED
4264825	Birth weight	Measurement	SNOMED					4064287	Large for gestational age fetus	Condition	SNOMED
4014465	Birth length	Observation	SNOMED								
2000000457	Birth length centile	Observation	SNOMED					4123497	<3	Meas Value	SNOMED
2000000457	Birth length centile	Observation	SNOMED					신규생성(서울C 3-9	Meas Value		
2000000457	Birth length centile	Observation	SNOMED					신규생성(서울C 10-49	Meas Value		
2000000457	Birth length centile	Observation	SNOMED					신규생성(서울C 50-90	Meas Value		
2000000457	Birth length centile	Observation	SNOMED					신규생성(서울C 91-97	Meas Value		
2000000457	Birth length centile	Observation	SNOMED					4131980	>97	Meas Value	SNOMED
4015277	Birth head circumference	Measurement	SNOMED								
2000000458	Birth head circumference centile	Observation	SNOMED					4123497	<3	Meas Value	SNOMED
2000000458	Birth head circumference centile	Observation	SNOMED					신규생성(서울C 3-9	Meas Value		
2000000458	Birth head circumference centile	Observation	SNOMED					신규생성(서울C 10-49	Meas Value		
2000000458	Birth head circumference centile	Observation	SNOMED					신규생성(서울C 50-90	Meas Value		
2000000458	Birth head circumference centile	Observation	SNOMED					신규생성(서울C 91-97	Meas Value		
2000000458	Birth head circumference centile	Observation	SNOMED					4131980	>97	Meas Value	SNOMED
4265556	Form of placenta	Observation	SNOMED								
36716289	Multiple birth order	Observation	SNOMED					4101844	Twin birth	Condition	SNOMED
36716289	Multiple birth order	Observation	SNOMED					4094046	Triplet birth	Condition	SNOMED
36716289	Multiple birth order	Observation	SNOMED					45765500	Quadruplet birth	Condition	SNOMED
36716289	Multiple birth order	Observation	SNOMED	4112230	First	Meas Value	SNOMED				
36716289	Multiple birth order	Observation	SNOMED	4217781	Second	Meas Value	SNOMED				
36716289	Multiple birth order	Observation	SNOMED	4324384	Third	Meas Value	SNOMED				

Sample standard-terminology mapping dictionary



Open-Call Research (NICU Discharge Record)

2024 — Research Using the NICU Discharge Record Extended CDM

- Call announced Sept 2024; one project selected, research launched Jan 2025
- Selected project: Developing a personalized early enteral nutrition protocol for very-low-birth-weight infants based on maturity and risk (PI: Prof. Heeseung Cho, KNUH)
- NICU Discharge Record–Specific Quality Assessment
Exploring the feasibility of data-quality assessment by comparing institution-level averages of key variables.
- NICU Discharge Record Data Items
Gestational age, Birth weight (incl. percentile), Apgar score (1, 5, 10 min), Intraventricular hemorrhage (IVH, incl. grade), MRI (findings — free text), Etc.



Open-Call Research (TBC)

2025 — Data-Use Open Call: Announcement & Selection in Progress

- Using CDM-extended NICU VitalDB data
- Using CDM-extended CXR DICOM data (in children with lower respiratory tract infection)

2026 — Echocardiography (DICOM) Data-Use Open Call Planned

· 희귀질환지원사업단 · 신규 연구 공모 제안요청서(RFP)

세부	수요조사분류	RFP 과제명	지원규모	지원기간	선정예정 과제수
	NICU CDM 활용	생체신호를 이용한 신생아실 환자의 혈압 예측모델 개발	NICU CDM 데이터 인프라 및 연구 지원		

1. 제안요청서

제출/제출처: 생체신호를 이용한 신생아실 환자의 혈압 예측모델 개발

지원규모 및 기간

- 사업 기간: ○ 사업비: ○ 선정 과제 수: ○ 사업기간 및 지원 범위는 심의위원회를 통해 조정할 수 있음 ○ 적합한 과제가 없는 경우 선정하지 않을 수 있음 ○ 활용 데이터: - 서울대학교병원 NICU에서 2021.06.02. ~ 2025.06.30. 동안 수집된 1,592 명 * 적중, 진단, 검사 결과 등의 데이터(생체 신호) 기반 NICU CDM 데이터 * 공백률(0.02%) 및 데이터(0.02%) 등의 생체신호 기반 NICU CDM 데이터

제안배경 및 필요성

- 사업 배경: - 현재 신생아 중 고위험(at risk) 신생아의 비율은 약 23%로 미려 높아지고 있음. - 고위험 신생아는 호흡기, 지체장애, 신생아, 장노, 신장질환, 출생한 신생아로 분류됨.

2025년도 Chest X-ray 영상 이미지를 포함한 CDM 데이터 활용 연구 공모

1. 내용

본 이진화 데이터의 경영전략 "인간 건강과 인류 사회 발전"을 실현하기 위한 기부금으로 운영 중인 소아암 희귀질환 지원 사업단은 희귀질환 어린이 환자들의 진단과 치료, 원인 규명을 돕기 위한 사업을 진행하고 있습니다. 그 일환으로 전국 어린이병원에서 CDM을 구축하고 있으며, chest x-ray 영상 이미지를 포함한 CDM 데이터를 활용하는 연구를 공모하고자 합니다. 선정된 연구 과제는 궁극적으로 궁극적 연구로 이어질 수 있도록 후속 협의를 통한 인프라 및 연구 지원이 있을 예정입니다.

2. 일정

구분	일자	비고
1. 소아 CDM 활용 연구 공모 공고	11월 24일	사업단 홈페이지 등
2. 공모 신청	12월 1일 ~ 수시 접수	전자우편을 통한 접수
3. 연구과제 공모 선정 심의	매월 정기 심의	선정위원회 구성하여 평가
4. 연구과제 공모 결과 안내	매월 정기 안내	제출 종료
5. 소아 CDM 활용 연구 진행	후속 협의	사업단 및 연구자

*일정은 변경조정이 가능합니다

3. 활용 데이터 : CDM 및 소아 하기도 감염 Chest X-ray 영상

- 배경 및 필요성: - 소아 하기도 감염은 국내·외에서 유급실 방문과 입원, 중환자실 치료의 주요 원인으로, 바이러스성 및 세균성 원인이 다양함 - 감염 질환의 적절한 예방과 대응은 병원·지역 간 차이가 크며, 이를 표준화된 데이터 기반으로 예방 분석할 필요가 있음 - CDM과 의료영상 데이터를 결합하면 질병 부담·진료 소모 분석 및 세부 예측 모델 등의 개발이 가능하여 임상 및 공공보건 정책에 기여할 수 있음
- 대상 환자군: 18세 미만의 소아 하기도 감염 환자
- CDM 활용 데이터 범위: - EHR: 순환기록, ICU 입실, 검사결과, 약물, 처치, 활력징후 등

Open-call announcement materials



Collaboration is always welcome

Korea Kids Network

Connecting pediatric data for better child health

7

hospitals

1.69M

pediatric patients

OMOP

CDM standardized

ECG · NICU · VitalDB
PFT · CXR · Echo

Multimodal Extension

PI Hee-Soo Kim, MD, PhD · Kwangsoo Kim, PhD

Suhyun Kim

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