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A practical approach to identifying early neonatal conditions in a de-identified database: National Health Insurance Research Database (NHIRD)

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BACKGROUND & OBJECTIVES

Background

Mother-baby linkage (MBL) is essential for longitudinal pregnancy cohort studies, enabling researchers to connect prenatal exposures with newborn outcomes. In Taiwan, the establishment of MBL and the capture of birth-related information rely on two administrative processes: *birth reporting* and *birth registration.*

First, the person who delivers the baby (usually a physician) is obligated to report maternal and neonatal health data within 7 days after delivery (i.e., ***birth reporting***) [1]. These data are compiled into the Birth Reporting Database (BRD), which provides comprehensive newborn outcomes at birth and serves as a reliable source for case ascertainment in birth, including live births and stillbirths (weighing ≥ 500 g or gestational age ≥ 20 weeks).

Second, newborn's parent(s) are required to register the birth within 60 days (i.e., ***birth registration***) and typically apply for National Health Insurance (NHI) enrollment at the same time. Once the newborn is assigned a personal identification number (ID), their health data become available in the National Health Insurance Research Database (NHIRD). Prior to this, healthcare services provided to newborns may be claimed and recorded under the parent's NHI coverage.

The delay in assigning a unique ID to newborn created a gap in retrieving early-life health data, particularly for clinical outcomes during the neonatal period (i.e., within 28 days after birth). To address this limitation, leveraging parental IDs may offer a feasible solution to retrieve neonatal healthcare data before MBL is established.

Objective

This study aimed to propose an alternative approach for identifying neonatal outcomes (including neonatal mortality) by leveraging parental IDs. The preliminary analysis focused on mothers with neonatal conditions.

METHODS

Data Source

- Medical claims data were obtained from the population-based NHIRD, which covers up to 99.6% of the Taiwanese population [2]. Maternal IDs were retrieved from the nationwide BRD. Mortality data were linked through the National Death Registry (NDR).
- All data were de-identified and linked using encrypted personal IDs while ensuring patient privacy [3].
- Data period spanned from 1st January 2022 to 31st December 2023.

Study design and outcomes

- Patients with neonatal conditions from the NHIRD or neonatal deaths from the NDR were linked to maternal IDs in the BRD (Figure 1) to assess the proportion of outcomes under maternal IDs.
- The analysis evaluated the proportion for all neonatal conditions and for a subgroup of neonatal infections (ICD-10-CM P35–P39).

Study population

Two cohorts were identified between 1 January 2022 and 31 December 2023:

- Patients diagnosed with neonatal conditions (ICD-10-CM: P00–P96) were identified from outpatient and inpatient visits in the NHIRD.
- Patients registered with causes of death related to neonates (Table 1) were identified from the NDR. Additionally, "*neonatal deaths"* within 28 days after birth were also identified by the data-source specific variable "newborn age = 00–27", which specifies the age at death in days.

Table 1. Codes for neonatal death in NDR

ICD-10-CM	Definitions
P00-P96	Conditions originating in the perinatal period (defined as "28 days after birth" based on NHI ICD-10-CM Coding Guideline)
Q00-Q99	Congenital malformations, deformations, and chromosomal abnormalities
R95 (data source-specific code)	Sudden infant death syndrome (SIDS)

Statistical analyses

- Descriptive statistics were used to summarize the coverage of the neonatal outcomes under maternal IDs.

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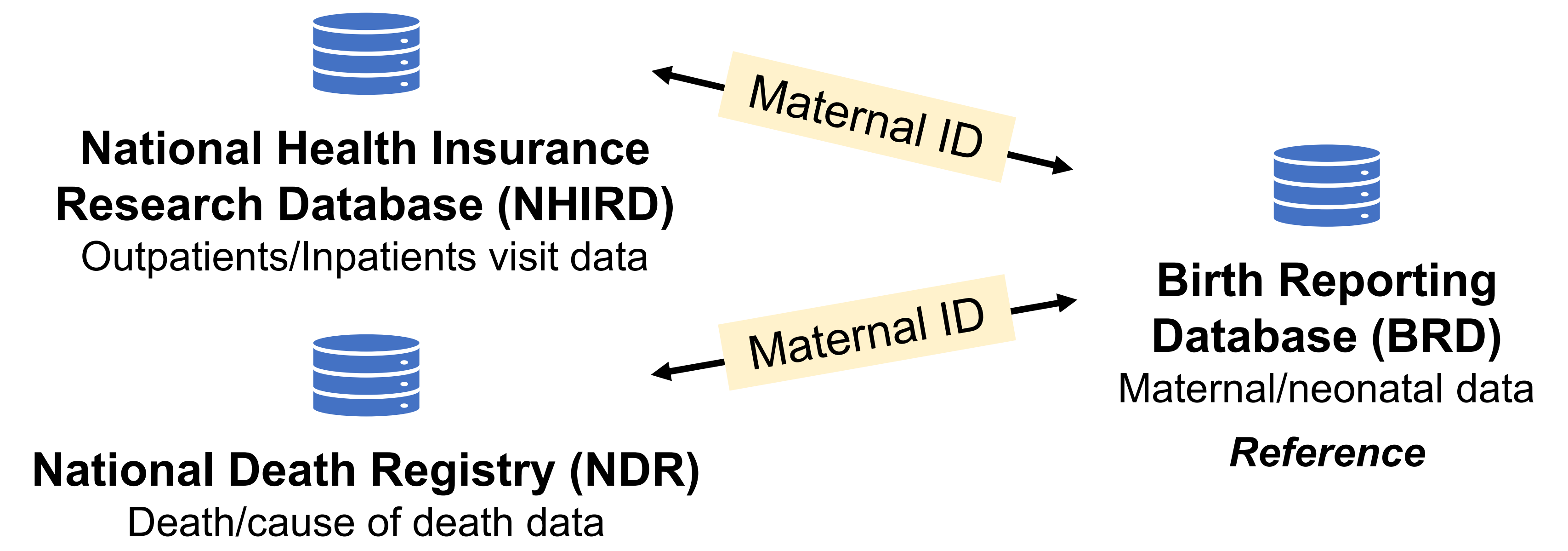

National Health Insurance Research Database (NHIRD)

Outpatients/Inpatients visit data

National Death Registry (NDR)

Death/cause of death data

Birth Reporting Database (BRD)

Maternal/neonatal data

Reference

Figure 1. The schematic data linkage using NHIRD and NDR with BRD

RESULTS

Neonatal conditions

- During 2022-2023, a total of 156,646 outpatient visits and 71,920 inpatient visits with diagnosis of neonatal conditions were identified, of whom 56.0% and 86.5% of IDs could be matched to the reference maternal IDs, respectively (Figure 2A). The proportions remained similar (50.6% and 86.1%) for neonatal infections (Figure 2B).

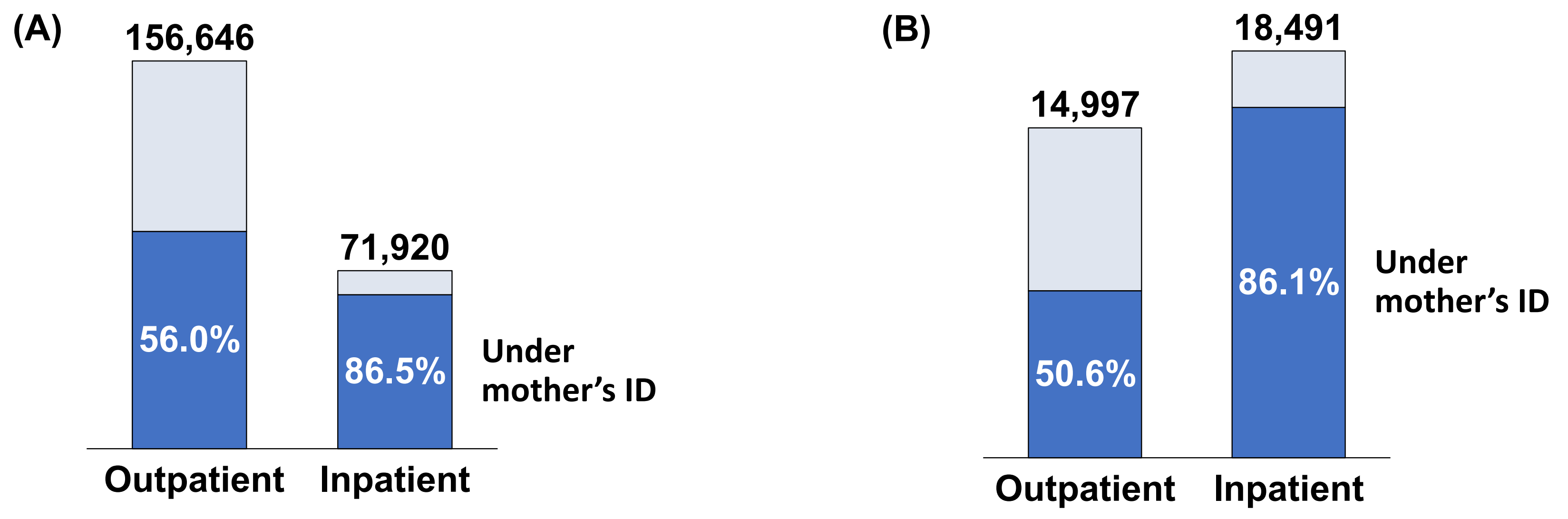

Figure 2. Outpatient and inpatient visits with diagnoses of (A) neonatal conditions and (B) neonatal infections

Neonatal deaths

- A total of 1,137 deaths attributed to neonates-related conditions (P00-P96, Q00-Q99, and R95) were identified. Of these, 91.8%, 30.4%, and 3.1% occurred within the first 28 days after birth, respectively (Figure 3).
- In a separate analysis, 760 neonatal deaths were identified based on age at death recorded in the NDR (Figure 4). Among these, perinatal conditions accounting for 79.1% of the cases.
- Notably, neither group could be matched to the reference maternal IDs in the BRD, suggesting that neonatal deaths were registered under individual IDs rather than maternal ones.

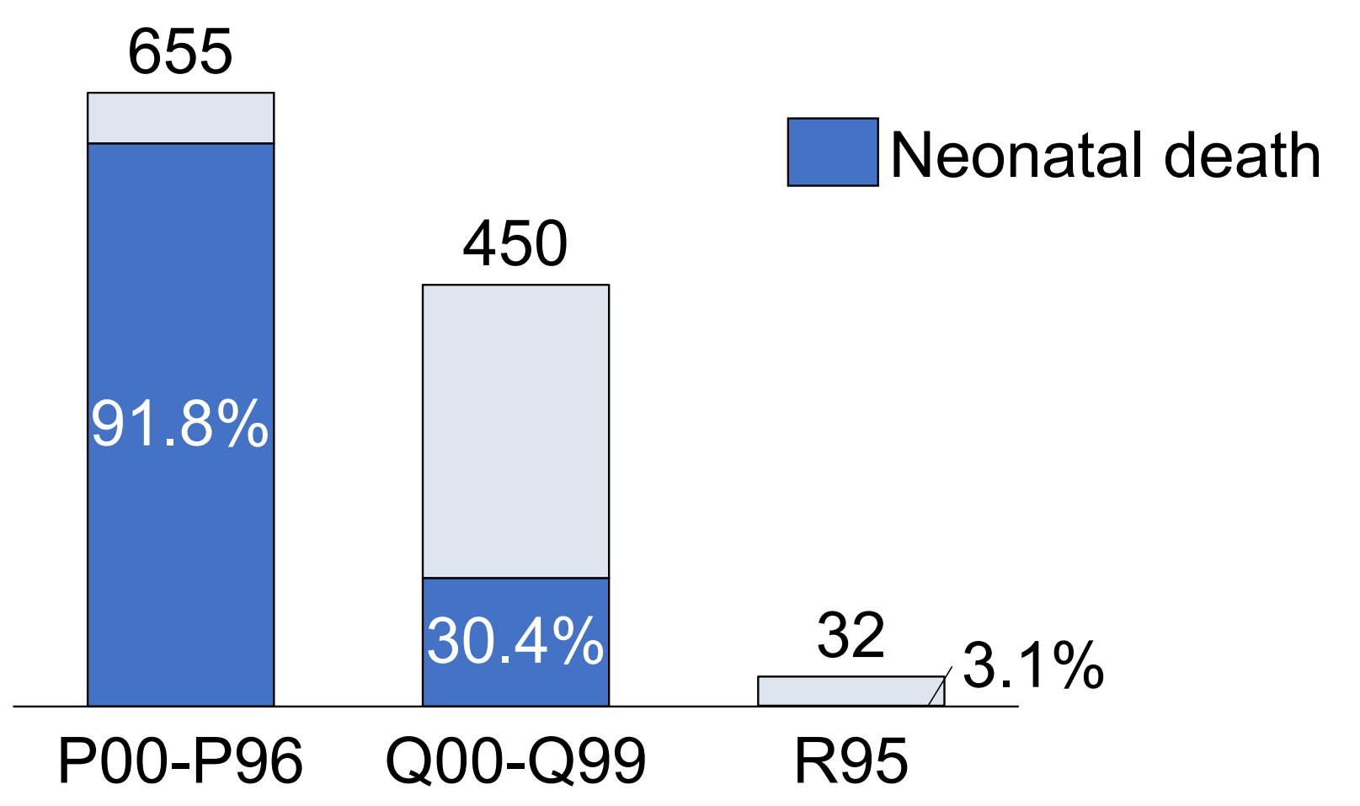

Figure 3. Percentage of "neonate death" among death with cause of neonate-conditions (N=1,137)

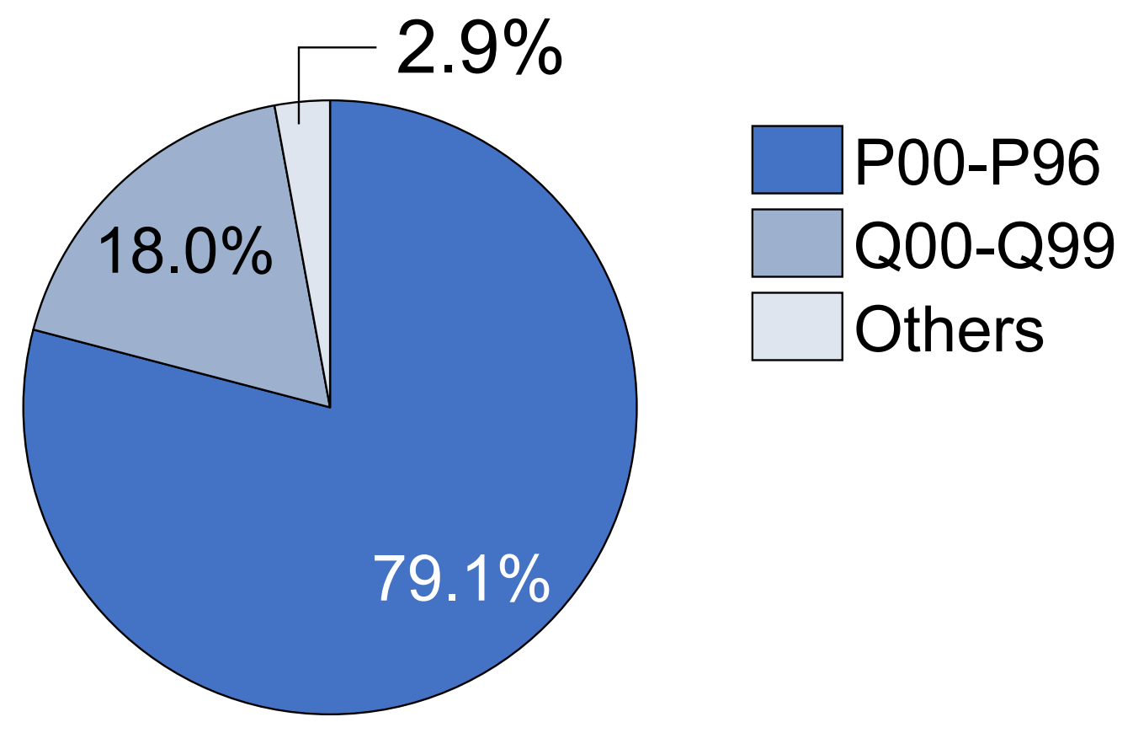

Figure 4. Distribution of cause of death among all neonate deaths (N=760)

CONCLUSIONS

- The study findings suggested that neonatal outcomes requiring hospitalization can be identified via maternal IDs before a neonate's personal ID was assigned, enabling longitudinal follow-up from pregnancy to neonatal period in the absence of MBL.
- In contrast, neonatal deaths were found to be recorded under neonates' personal IDs, which then required MBL to link maternal exposure. The Maternal and Child Health Database previously supported this linkage but was discontinued in June 2024 and replaced by the Ministry of Interior's Birth Registration Dataset [4], for which access details remain unpublished.
- Further research may explore linking family IDs through beneficiary relationships between NHI insurers and insured individuals to enhance neonatal outcome identification without MBL.

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