

# Information Architecture for Perinatal Registration in the Netherlands

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## ABSTRACT

In the Netherlands, the perinatal registry has undergone significant changes in the past decades. The purpose of this article is to describe the current health care information architecture for the national perinatal registry, including how the national data set is arranged and how electronic messages are used to submit data. We provide implications for women's health care providers based on the creation and implementation of the Dutch perinatal registry system.

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In 1971, a registration for vital birth statistics was created in the Netherlands (van Hemel, 1977), and since that time the process for submission of these data has undergone significant changes. The perinatal registry holds national vital statistics on pregnancy and birth and is used to create quality indicators and feedback for clinicians and to track national statistics. This multiprofessional tool contributes significantly to improved outcomes for women and infants. Since 1971, four major changes occurred in the perinatal registry. The first change was from paper-based to electronic data submission, including the use of one system in which midwives, general practitioners, obstetricians, and pediatricians contribute perinatal data to one national registry. This registry holds vital national statistics, including birth certificate data and data about the care delivered. In the past it proved to be more effective to pool data from all involved specialty areas than to pool different records into one case per pregnancy.

The second change was the national adoption of Health Level 7 version 3 (HL7 v3; 2016) messaging for electronic submissions. A third major change originated from different parties and led to the current (2014) consensus on the

data set, codes, and value sets (National Information and Communication Technology Institute for Health [Nictiz; *health is Zorg in Dutch, hence Nictiz*], 2016a). Given these changes, the national registry is now faced with an increased diversity in submission formats and changes in the data sets over the years before final consensus was reached. The adaptation to the new standards and their implementation in electronic patient records takes time and is carried out at a different pace among hospitals, practices, and vendors. In addition, there is an increased demand for the use of perinatal data for multiple purposes. Finally, the fourth change is the current new information architecture described here.

In this article, we describe outcomes of the consensus among Dutch midwives and obstetricians, how the national data appear, and how the HL7 v3 messages are used to submit data to the national registry. We also identify the form and structure of the current health care information architecture for the Dutch national perinatal registry, Perined. This new health care information architecture is designed to allow Perined to increase services in the upcoming decades and to support the growth of high-quality care.

**The Netherlands has collected vital birth data from perinatal professionals on a national level for decades and has used these data to derive vital national statistics.**

## The History of Perinatal Registries in the Netherlands

In 1971 van Hemel established the first obstetric database for regional birth statistics (referred to henceforth as the Dutch perinatal registration) in the southwest part of the Netherlands (van Hemel, 1977; van Hemel et al., 1978). The Dutch perinatal registration was created because researchers needed population-based data related to pregnancy and birth with which to improve quality of care. By 1982 the Dutch perinatal registration was the national obstetric registration database for hospitals, referred to as Landelijke Verloskunde Registratie (LVR2), and was used to maintain and archive vital records for hospital-based birth statistics. The data captured in the LVR2 database were related to the reason for admission, gestational age, fetal characteristics, medications, and birth events and included duration of pregnancy; the sex, birth weight, length, and skull circumference of the newborn; feeding method (breastfeeding or formula-feeding); and procedures and medications used during the childbirth episode. In 1985, the registration began to include electronic data from midwives in a version called LVR1 that was related to home births and births attended by general practitioners. The general practitioner records were referred to as the LVR-h. The LVR1/LVR-h versions contained some similar data also included in the LVR2, with notable differences, particularly related to physiologic normal pregnancy and subsequent birth.

The Netherlands has a long tradition of home births, and of the 180,000 births annually, almost one third occur at home (Perinatal Registration Netherlands, 2011). A trend toward hospital births has been noted, with 43.5% home births in 1999, 32.7% home births in 2008, and 30.1% home births in 2012 (Perinatal Registration Netherlands, 2011, 2013). In 1992, pediatricians and neonatologists established a national neonatal registration known as the Landelijke Neonatale Registratie (LNR). Within the LNR, four separate registrations, LVR1m, LVR-h, LVR2, and LNR, each used specific electronic messaging formats. These formats could be used for one individual record or for batch submissions of entire groups of records. The first significant

change in processes for these separate registrations was in 2001 with the foundation of the Perinatal Registration Netherlands (PRN), which established an electronic database for maternal and infant characteristics so that providers, including midwives, general practitioners, obstetricians, and pediatricians/neonatologists, could contribute to a single national registry supported by their four professional organizations.

Since 2001, the full perinatal registration consists of up to four individual records (one per professional that detail their individual episode[s] of care) that were combined into unique cases at the national level and further analyzed (Perinatal Registration Netherlands, 2013). Since 1985, all professionals in the Netherlands use electronic health record (EHR) systems for data extraction and file submission related to pregnancy, labor, birth, and postpartum care. The data types submitted to registrations contain numeric values (e.g., birth weight, Apgar scores) or data entered from a defined value set (such as level of education), pick lists (such as the applicable medical diagnoses), and episodic care visit dates (such as the birth date).

## Developing Health Information Interoperability

A second change for perinatology was the use of HL7 v3 messaging to exchange data electronically. Health Level 7 publishes and promotes standards for data sharing and exchange, otherwise known as semantic interoperability. In 2000, the perinatology domain was selected as a pilot to test the use of HL7 v3 messages as the standard for the national health care information exchange format in the Netherlands (de Graaf et al., 2007; Goossen et al., 2003; IPZorg, 2000).

Each HL7 v3 message was organized to include the following parts: dynamic, structural, vocabulary, and technical implementation. The dynamic part included standards for workflow and interactions between organizations, professionals, and their systems. The structural part included specifying each single data element and representing the element by a class (grouping) in a class model. A class can best be compared with a virtual Lego block with unlimited availability to allow the creation of many solutions. The box of virtual blocks (classes) in HL7 is called the reference information model, with core elements that are used to identify *entity*, *role*, *role link*, *participation*, *act*, and *act-relationship*. For

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