

RESOLUTION OF THE REVIEW PROCESS OF THE CODING OF EMPTY NOSE SYNDROME IN THE RePER

April 28, 2026

1. Executive Summary

This document presents the result of the review process of the coding of Empty Nose Syndrome (ENS) in the Registry of Patients with Rare Diseases (RePER), following the technical proposal submitted by the Spanish Association for Empty Nose Syndrome (AESNV).

As a result of this process:

- ENS has been decoupled from category J31.0 – Chronic rhinitis, as it does not adequately reflect its clinical nature.
- RePER has adopted a specific internal classification within its expanded coding system: *J348 01 – Empty Nose Syndrome*. Furthermore, RePER has clarified that its coding system is for internal use and should not be applied in general clinical practice.
- RePER has indicated that, in the context of clinical practice, the code *J34.8 – Other specified diseases of the nose and nasal sinuses* may be used as a classification option in the absence of a specific code.

2. Context

In December 2025, the Spanish Association for Empty Nose Syndrome (AESNV) submitted to the Registry of Patients with Rare Diseases (RePER), under the Instituto de Salud Carlos III, a technical proposal for the review of the coding of Empty Nose Syndrome (ENS).

This proposal, developed on a clinical, pathophysiological, and regulatory basis, highlighted the inadequacy of its initial classification under code CIE-10-ES (Spanish adaptation of ICD-10): *J31.0 – Chronic rhinitis*, as it did not reflect the true nature of the syndrome.

Within CIE-10-ES, both code *J31.0 – Chronic rhinitis* and code *J34.8 – Other specified diseases of the nose and nasal sinuses* are included within *Chapter 10. Diseases of the respiratory system (J00–J99)* and, in turn, within the subchapter *Other diseases of the upper respiratory tract (J30–J39)*.

This block includes various clinical entities of the upper respiratory tract, including both inflammatory conditions and structural or functional alterations.

Methodological note:

This document has been prepared based on the process of technical communication carried out between AESNV and RePER during the period October 2025 – April 2026.

3. Outcome of the review process by RePER

Following the analysis of the documentation provided by AESNV, the technical team of RePER carried out a reassessment of the classification initially assigned to ENS, adopting a series of decisions that represent a relevant step forward in its recognition within the system.

Firstly, RePER has accepted the need to reclassify ENS outside the category of chronic rhinitis (J31.0), as it does not adequately reflect its clinical nature.

As a result, a specific internal coding has been assigned within its expanded system, under the designation *J348 01 – Empty Nose Syndrome (ENS)*, allowing its differentiated identification within the registry (see Figure 1).



The screenshot shows the RePER website interface. At the top, there are logos for the Spanish Government, the Ministry of Science, Innovation and Universities, and the Instituto de Salud Carlos III. The main header includes the RePER logo and the text 'Registro de Pacientes de Enfermedades Raras'. A navigation bar shows 'Inicio' and 'Registro Pacientes'. The main content area is titled 'Información de la Enfermedad' and displays 'ENFERMEDAD: Síndrome de Nariz Vacía (SNV)'. Below this, there are tabs for 'Info. y Codificación', 'Asociaciones', 'Cuest. Enfermedad', and 'Enlaces de Interés'. The 'Info. y Codificación' tab is active, showing 'Datos CIE-10'. A table lists the following information:

Nombre Enfermedad	CIE-10	CIE-10 Ampliado
Síndrome de Nariz Vacía (SNV)	J348	01

Below the table, there is a 'Gen' field with an empty input box.

Figure 1. Extract from RePER showing the classification of ENS and its associated coding
Source: Registry of Patients with Rare Diseases (RePER). Instituto de Salud Carlos III.

This change is based on the understanding that ENS cannot be classified as an inflammatory condition, but rather as a distinct clinical entity, with specific characteristics that justify a different classification framework.

Furthermore, RePER has clarified that its coding system incorporates an adaptation of CIE-10-ES developed by the Institute for Research on Rare Diseases (IIER), for registry purposes.

In this context, it has explicitly stated:

“Our coding does not include dots and incorporates an expanded CIE-10 code, created by IIER and used only by us. Therefore, it would not be appropriate for others to use our coding.”

This clarification highlights that the coding used within RePER corresponds to an internal system, designed exclusively for use within the registry, and not for application in routine clinical practice.

Consequently, it is essential to distinguish between registry coding, used for epidemiological purposes, and standard clinical coding, which should continue to be based on official CIE-10-ES codes.

In relation to clinical practice based on CIE-10-ES, RePER has indicated that code *J34.8 – Other specified diseases of the nose and nasal sinuses* may be used as a classification option for ENS, as it is more consistent with its structural and functional nature (see Figure 2).



Figure 2. Extract from CIE-10-ES showing category J34.8

Source: Ministry of Health. Electronic edition of CIE-10-ES. Available at: <https://www.eciemaps.sanidad.gob.es>

4. Implications of the coding review

The review of ENS coding within RePER introduces relevant changes in its classification, by removing it from the category of chronic rhinitis (J31.0) and placing it within a framework more aligned with its clinical nature.

From a technical standpoint, this modification has direct implications for how ENS is identified, recorded, and analyzed within the system.



This change enables:

- greater coherence between classification and the pathophysiology of the syndrome
- more precise identification of cases within the registry
- improved quality and consistency of recorded data
- a more appropriate basis for the development of specific epidemiological analyses
- better differentiation of ENS from other clinical entities within the same CIE-10-ES block

Furthermore, in the context of clinical practice based on CIE-10-ES, the availability of categories more aligned with the nature of ENS introduces a more consistent coding framework with its clinical characterization, contributing to greater precision in its recording and classification in clinical and diagnostic reports.