

OFFICIAL STATEMENT

On the removal and exclusion of patient testimonies
on social media by healthcare professionals

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In the context of the European Patients' Rights Day, the Spanish Association for Empty Nose Syndrome (AESNV) considers it necessary to present an institutional reflection on a practice that is becoming increasingly frequent in the digital healthcare environment: the removal of patient testimonies in publications by healthcare professionals on social media.

In recent weeks, AESNV has received multiple communications from patients reporting the removal of comments — respectful and based on real experiences — in publications related to nasal procedures, particularly turbinate surgery. In many cases, these testimonies describe complications, sequelae, or outcomes different from those presented in such publications.

This phenomenon should not be interpreted as an isolated incident, but rather as a concerning trend in the way medical communication is being managed in digital environments.

Content moderation is a legitimate practice when its objective is to preserve respect and the quality of dialogue. However, there is a clear difference between moderating content and systematically excluding certain clinical realities. When patient testimonies reflecting adverse experiences are removed, access to relevant information is limited and an incomplete representation of the outcomes associated with certain procedures is created.

In this context, it is particularly relevant to recall that the European Charter of Patients' Rights recognizes, among others, the right to information, the right to informed consent, the right to safety, and the right to avoid unnecessary suffering. These rights require real access to truthful, balanced, and complete information.

The patient experience constitutes an essential component in the evaluation of outcomes and in the improvement of healthcare quality. Systematically excluding testimonies that reflect complications or adverse outcomes does not eliminate their clinical existence, but it does make it more difficult for other patients to fully understand the risks associated with certain procedures.

Healthcare communication on social media significantly influences the perception of safety and the decision-making of patients. The removal of unfavourable testimonies may contribute to building a partial image of clinical reality and weaken trust in healthcare professionals and in the healthcare system.

In the case of Empty Nose Syndrome (ENS), this issue takes on particular relevance. It is a complex condition, frequently underdiagnosed, whose visibility largely depends on the ability of patients themselves to share their experiences. The removal of these testimonies contributes to perpetuating clinical unawareness, delaying diagnoses, and increasing the isolation of those affected.



From AESNV, we consider that transparency and active listening to patients are fundamental pillars of medical practice. The systematic exclusion of experiences that do not fit within a positive narrative does not contribute to the advancement of knowledge nor to patient safety.

This statement does not intend to question the work of healthcare professionals nor to create confrontation, but rather to highlight the importance of responsible, balanced communication aligned with patients' rights.

As a patient association, we defend the right for all experiences — including those reflecting adverse outcomes — to be part of the informational space, always based on respect and truthfulness.

AESNV reiterates its willingness to collaborate with healthcare professionals, institutions, and organizations to promote more transparent communication and to move towards a safer, more ethical model of care centered on clinical reality.

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