Silenced data: How banning words undermines real-world evidence in medical writing

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Abstract
Executive orders (EOs) issued by the President of the United States can significantly shift federal research priorities, funding allocations, and public health directives, thereby influencing which medical topics receive attention and resources. EOs also affect the transparency, availability, and regulation of medical data. In this article, we report how language censorship brought about by recent EOs affects the collection, interpretation, and communication of real-world evidence. Real-world evidence depends on accurate, inclusive, and standardised terminology. Banning certain words undermines data integrity and scientific utility.

Image: Freepik

US executive actions on real-world evidence, 2016–2025

This year has witnessed a revival of what had already happened to a lesser extent in 2017, that is, the disappearance of certain words from scientific documents and official government websites in the United States, but this time it has occurred with much greater intensity. These are the so-called "word bans" that followed the executive orders of the White House.[1,2] However, the White House denied the existence of a list of prohibited words.[3] An official Executive Order (EO) banning specific words does not, in fact, exist.[4,5] To grasp what happened, we must first understand the EO mechanism. An EO is an official act issued by the President of the United States. Although these orders are not laws, they are a primary tool by which the President can direct the operations of the federal government.

These policies have shaped the reporting of clinical and epidemiological information – including real-world evidence (RWE), defined by FDA as clinical evidence about the use and benefits/risks of medical products derived from analyses of real-world data (such as electronic health records, insurance claims, and patient registries).[6] The US executive decisions, ranging from memoranda to EOs, from 2016 to date, that have a significant impact on RWE are shown in Figure 1 and described in Table 1.

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The "banned" words

In March 2025, *The New York Times*,[7] based on publicly available texts of the EOs published in the US Federal Register, compiled a list of 197 words or concepts that agencies had flagged to limit or avoid, resulting from EOs issued this year.[8] The list, available at the *New York Times* website, starts with "accessible", ends with "women and underrepresented", and includes many terms related to diversity, equity, and inclusion (DEI), as well as climate science. These words and phrases were being removed from websites and replaced with others deemed acceptable by the current administration. *The New York Times* also provided examples of how words had been deleted, such as the visual depiction of changes to a memo about Head Start, a US programme to

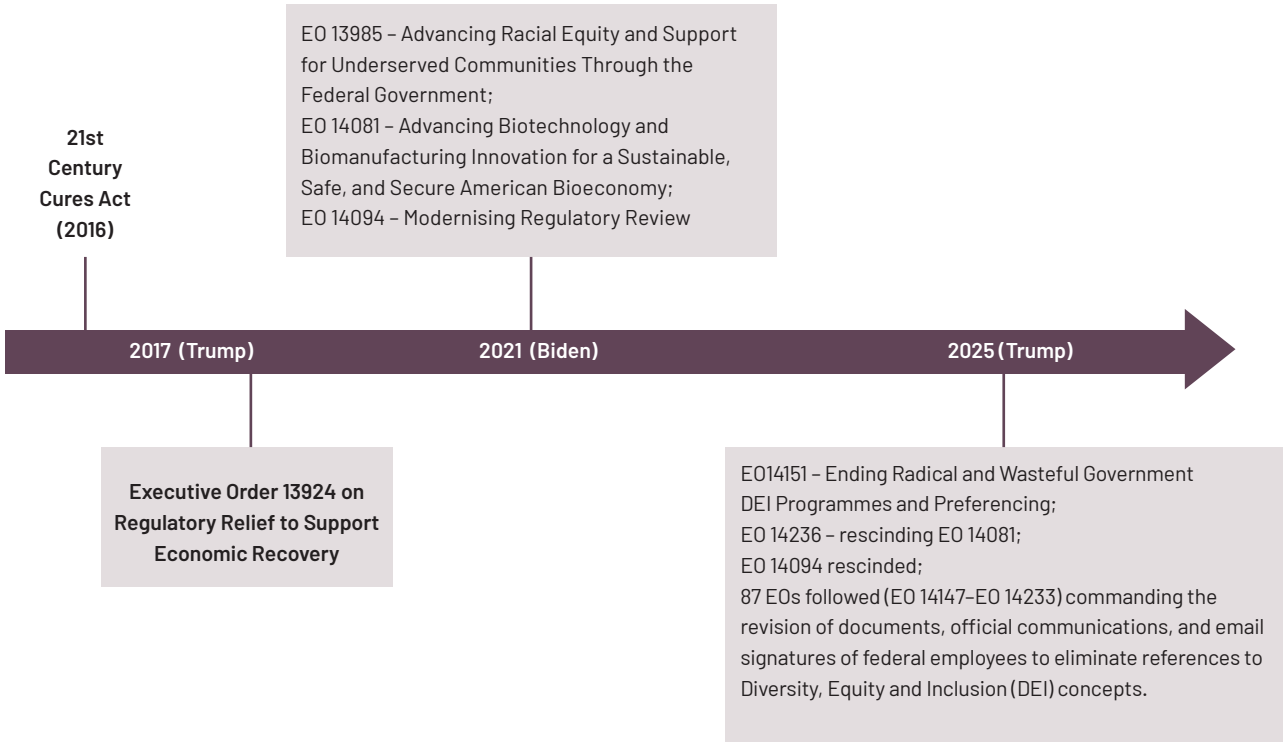

Figure 1. Figure that reproduces with a timeline the different Executive Orders and Memorandum during Biden and Trump Administrations around DEI

promote early childhood education for children in lower-income families:

> The last year has brought significant challenges to the Head Start workforce. ~~The COVID-19 pandemic has had a disparate impact on under-resourced communities including many of those served by Head Start programmes.There has also been heightened attention to racial injustice in our country, which has led to calls for major reforms to address long-standing societal inequities. These are particularly important concerns for OHS and the Head Start workforce.~~ All staff have been impacted by COVID-19. ~~Further, 60% of Head Start teaching staff are Black, Indigenous and people of colour, and 30% have a primary language other than English.~~ As such, OHS is committed to a culture of wellness that includes holistic support for the entire Head Start workforce.

Darby Saxbe,[9] a professor at the University of Southern California, posted on social media an example of how specific uses of language were being reviewed to determine which health grants should be canceled (Figure 2). The decision tree was sent to, among others, all programme officers at the National Science Foundation (NSF).[10]

As as a result of the White House EOs, operators of individual agencies were tasked with deciding whether a term should be removed, replaced, or retained, depending on the context. In addition to their hierarchical administrative organisation, the agencies of the federal government of the United States are interconnected at multiple levels,[11] through hyperlink and datalink paths across the web and linked open data (LOD). Therefore, changes in the semantics of any one of the sites with the .gov extension can indirectly influence the interpretation or use of terms in other .gov-linked sites, especially where there is semantic overlap or hyperlink-based data referencing. Changes in one site do not automatically update others, but they can cause misalignment, misunderstanding, or require re-interpretation downstream. Thus, there are many opportunities for inconsistent or contradictory uses of terminology and phraseology, across governmental agencies and contexts.

One of the affected datasets is CDC's Behavioral Risk Factor Surveillance System (BRFSS),[12] which is one of the most widely used national health surveys and has been ongoing for about 40 years. BRFSS has been used for decades to inform policymakers, the media, and the public on a wide range of health topics, such as obesity rates, access to breast cancer screenings, vaccination rates, and the proportion of people with pre-existing conditions. With sampling in every state, BRFSS data are particularly helpful for understanding health issues in low-population states and rural areas. It was briefly taken offline and later returned without its questionnaires or codebooks. However, without that documentation, researchers cannot verify how variables were measured or replicate analyses, undermining the integrity of any RWE derived from those data.

In total, roughly 8000 federal web pages disappeared from public view (some later returned with warning banners like "CDC's website is being modified to comply with President Trump's Executive Orders") but some

Year	EO / Memo	Description
2016	**21st Century Cures Act**	Mandated the FDA to evaluate how RWE can support approval of new indications for approved drugs and post-approval study requirements. A major legislative foundation for RWE.
2020	**Executive Order 13924 on Regulatory Relief to Support Economic Recovery**	Prioritised deregulation and reduction of data/reporting burdens, which may have limited RWE infrastructure development.
2021	**EO 13985 – Advancing Racial Equity and Support for Underserved Communities Through the Federal Government**	Promotes equity in data collection and health research, which enables inclusive RWE generation and use.
2021	**Memo: "Restoring Trust in Government Through Scientific Integrity and Evidence-Based Policymaking."**	Federal policy must be "guided by the best available science and data" and "scientific findings should never be distorted or influenced by political considerations."
2021–2024	**FDA RWE Guidance Series (e.g., on data standards, study design, and regulatory use)**	Though not EOs, these guidance documents support and operationaliSe the RWE programme under the Cures Act.
2022	**EO 14081 – Advancing Biotechnology and Biomanufacturing Innovation for a Sustainable, Safe, and Secure American Bioeconomy**	Encourages data innovation and evidence generation, including the use of RWE for regulatory and clinical applications.
2024	**EO 14094 – Modernising Regulatory Review**	Promotes evidence-based decision-making, encouraging agencies to use modern data approaches, potentially including RWE.
2025	**EO 14151 – Ending Radical and Wasteful Government DEI Programs and Preferencing**	Targets diversity programmes that are essential to equitable RWE generation; may roll back inclusive data strategies.
2025	**EO 14236, rescinding EO 14081. EO 14094 rescinded**	Deregulatory moves reducing support for RWE, particularly those rooted in DEI, data modernisation, or government health innovation.

Table 1. Executive orders and memoranda with implications for real-world evidence

President Trump's first term was from January 2017 to January 2021, then he was returned to office in January 2025. President Biden served in the 4 years in between.

Box 1. Partial list of US federal health data that had been taken offline at least temporarily

US Centers for Disease Control and Prevention (CDC): AtlasPlus; an interactive database with about 15 years of surveillance data for HIV, viral hepatitis, sexually transmitted diseases, and tuberculosis, as well as data on the social determinants of health.

PEPFAR Data Dashboards: PEPFAR, the US global HIV/AIDS Programme, comprehensive, up-to-date online data portal of program budgets and expenditures by country and service category.

Demographic and Health Surveys (DHS) databases: Data downloads from the DHS, an ongoing set of nationally representative household surveys supported by USAID, the US, international development agency, with population, health, HIV, and nutrition data from more than 90 countries.

Foreignassistance.gov: The US government's website with all foreign assistance data by country, budget, expenditure, programme

Area Health Resource Files: a resource of data on health professionals, hospitals, and economic CDC's Social Vulnerability Index: Census-based socioeconomic data used for disaster planning, response and recovery

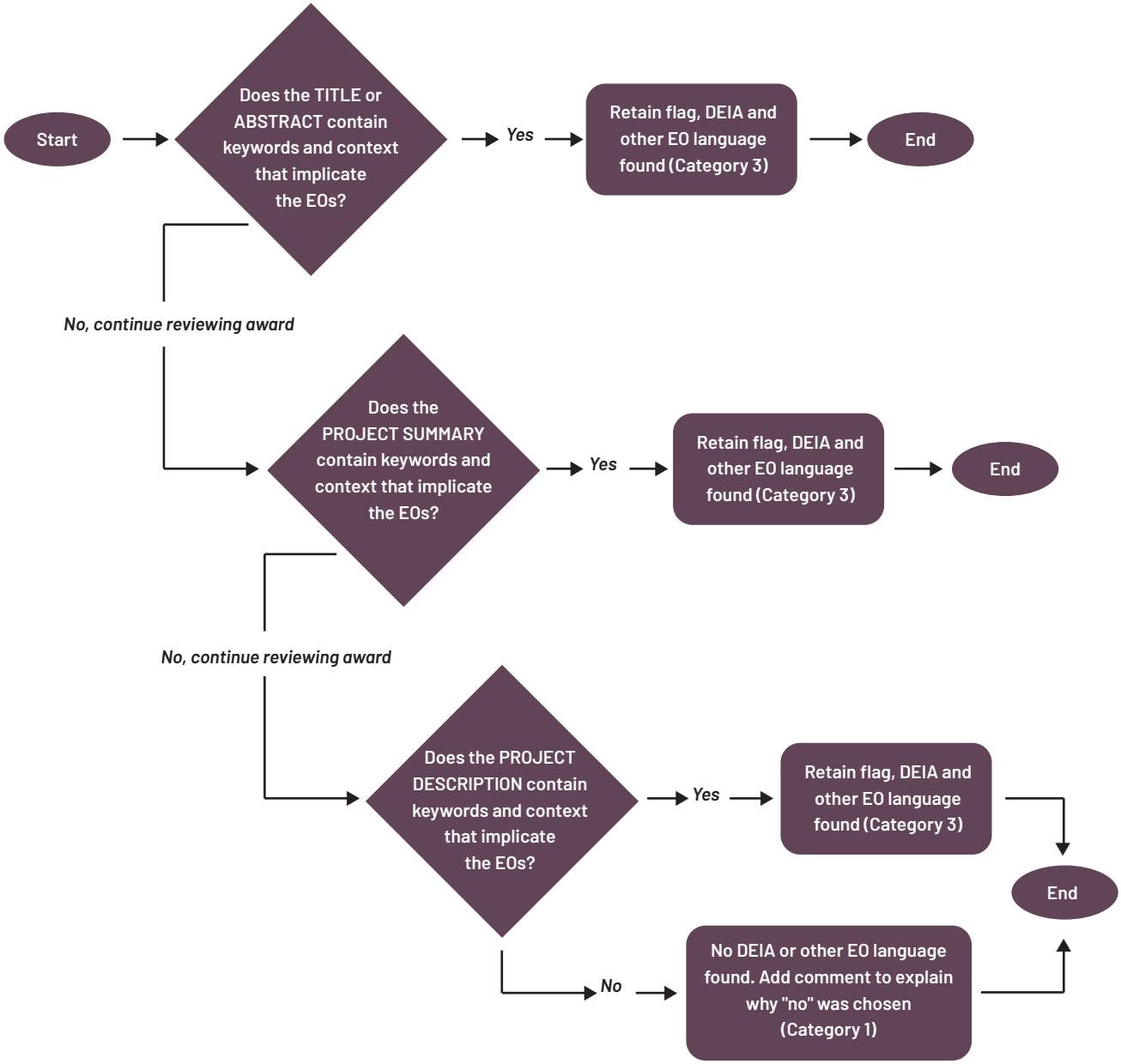

Figure 2. A decision tree distributed to program officers at the National Science Foundation to consider whether certain grants should be cancelled to comply with policies of the Trump Administration

A university professor posted the original image on social media. It was updated by the journal to improve clarity of the low-resolution image.

crucial websites are still not available (e.g., https://reproductiverights.gov/).[13] A list of federal health data sites that were at least temporarily taken offline and/or later altered is provided in Box 1.

"Bias" as a banned word

The term *bias,* far from being a hallmark for DEI topics only, is a foundational concept in knowledge and science. The phrase "cognitive bias" was introduced in the early 1970s by psychologists Amos Tversky and Daniel Kahneman to indicate systematically flawed patterns of responses to judgment and decision problems.[1] In 2002, Kahneman was awarded the Nobel Prize in Economics with the motivation "for having integrated insights from psychological research into economic science, especially concerning human judgment and decision-making under uncertainty".[15]

In medicine, too, human judgement and decision-making under uncertainty play pivotal roles – by patients, physicians, healthcare professionals, or scientists. Indeed, an increasing number of cognitive biases, from framing to anchoring to status-quo bias, have been recognised in medical science and practice over the last decades.[16]

A PubMed search using the terms *bias* and *human research*, thus excluding animal and pure laboratory research, yielded over 68,000 results from years 1966–2025, over 65,000 of them from years 2000–2025. The medical community at large is now aware that our attempts to understand reality are flawed, i.e., biased, and accounts for those biases, routinely

implementing corrective measures. Banning the word *bias* equates to sabotaging efforts to understand reality as it is, and RWE as its most appropriate measure.

How RWE is related to terminology

Three key regulatory elements must be in place for RWE to be effective: RWE regulatory framework, data quality and standards guidance, and study methods guidance. We focus here on the second element: data must be available, accessible, and fit for use. And, possibly, even improved upon: initiatives for ensuring high-quality RWD availability, access, standardisation, and methodological rigour have been advocated in pursuit of ever higher-quality RWE. This is even more true now in the era of big data. The Big Data Task Force was created in 2017 jointly by EMA and HMA (Heads of Medicines Agencies) to tackle the challenges posed and reap the opportunities offered by big data.[17]

Data standardisation relies on terminology, defined by the NIH as "a systematically organised set of terms, concepts, and codes used in health care to describe clinical conditions, procedures, medications, and other healthcare-related topics in a consistent and uniform manner, while a term is defined as "human readable text description that can act as the anchor meaning for the concept".[18] So, though a term does not equate with a concept, the two are inextricably bound. The loss of a term starves the concept anchored to that term and, vice-versa, the free usage of a term is instrumental for the anchored concept to be circulated and elaborated on.

Patient demographics

In medicine, baseline data on demographics are the important starting point, including data on gender, race, and ethnicity. In March 2024, the Federal Register published the Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity[19] to improve the quality and usefulness of federal race and ethnicity data. The document recommends that information on race and ethnicity be collected using a single question that combines both, moving from two separate questions. This comes as a consequence that "since 1980, responses to the decennial census in each subsequent decade have shown increasing non-response to the race question, confusion, and concern from the public about separate questions on ethnicity and race". The Standards now define seven race or ethnic groups all of them to be used alone or in combination according to three different Approaches, plus the newly introduced "multi-racial and/or multiethnic group" introduced in Approach 3.

The updates, therefore, try to reflect the current multifaceted reality to the best of their capabilities. They are inspired by the idea that templates should reflect reality, not reality be moulded to adjust to templates. Similarly, the NIH directs the use of Office of Management and Budget (OMB) census categories with self-identification for clinical trials, to make such artificial settings, as clinical trials are, as realistic as possible. Any removal of the terms indicating ethnic groups as commanded by the US administration would yield data that do not accurately describe reality. What is more, the removal of the very terms "race" and "ethnicity", as stated in the word bans, implies that it is deemed that neither concept has any relevance in medicine. This is known to be untrue for either genetic, environmental, social or cultural reasons, often for some or all of them combined.

The word bans will deprive PRO materials developed in the US of a wide range of commonly used terms, which are meaningful and unequivocal to patients and health care providers alike.

Medical outcomes

Another key set of data in medicine are outcome data. Medical outcomes in general can differ due to variations in drug pharmacokinetics or pharmacodynamics, or both, based on different age, race, and ethnic groups, clinical and other conditions, as well as genetic variants and gender. In particular, evidence of drug effects differing by gender has been documented for a long time in both clinical trials and real-life settings. A UK general practice study, combining 48 national cohort studies of newly marketed drugs, and comprising over 500,000 patients, reported that suspected adverse drug reactions to drugs are 60% more common in women than in men.[20] Drug gender differences exist in effectiveness, too. Low-dose aspirin tested on almost 40,000 patients has no significant efficacy on the risk of myocardial infarction or death from cardio-vascular causes in women, as opposed to results in men.[21] It was proven that dosing, too, can require massive adjustments in women.[22] Given the broad range of proven gender differences in drug effects, the amount of data available from both clinical trials and real-life practice, and the long time for which such knowledge has been around, gender stands out as a parameter that cannot be overlooked in medicine at any stage. A ban on the words "woman, women" would make it impossible to present data by gender, thus completely failing to reflect reality for either men or women.

Patient-reported outcomes

Finally, word bans would affect situations that we have come to realise more recently. Although the English language holds a global standing and is often the source language for translation, the vast majority of patients worldwide routinely receive and provide medical information in their own language, i.e., a language other than English. This fact will remain for the future, dictated by reality and mandated by national legislations. The last few years have seen a considerable effort in linguistic validation of medical translations which directly or indirectly target patients.

In particular, linguistic validation (LV) of patient-reported outcomes (PROs), such as questionnaires and rating scales, is a critical component in modern clinical research and, increasingly, in real-world studie.[23] Linguistic validation is a process that ensures that translated content accurately represents the source while being culturally and linguistically appropriate for the target population. LV ensures that PRO instruments maintain linguistic accuracy, cultural relevance, and conceptual equivalence to the original version. The process involves a) forward translation and back translation to preserve meaning; b) cognitive debriefing with target-language patients to validate comprehension; c) in the case of multinational trials, regulatory alignment with the FDA, EMA, and other agencies that require proof of equivalence.[24]

The word bans will deprive PRO materials developed in the US of a wide range of commonly used terms, which are meaningful and unequivocal to patients and health care providers (HCPs) alike, thus rendering source texts less

Image: Freepik

comprehensible to patients, and translations either non-viable or invalid. The number of viable source texts for PRO translations will drop, and this will impact patients in real-life practice worldwide.

Reactions in defence of RWE integrity

There have been reactions from US scientists aimed at preserving the integrity of real-world evidence (RWE), including the reversal of language bans, the republication of vital datasets, and the reaffirmation of evidence-based standards in agency guidelines.

Some concrete initiatives to defend RWE integrity are as follows:

- Scientists, advocates, and institutions are mobilising to protect data and defend the principles of evidence-based research. To save federal health websites and databases, researchers are using different tools, including downloading datasets, scraping websites and archiving them with the Wayback Machine,[25] which is an initiative of the Internet Archive, and enables users to see how websites looked in the past.
- The Association of Health Care Journalists protested the removal of public health data "at a time when the rise in chronic illnesses and harmful behaviors among young people is at the top of the national agenda".[26]
- The American Medical Writing Assocation reacted by reaffirming its values and mission relating to DEI in a message to members.[27]

In the rest of the world, scientists and researchers are showing solidarity with their US colleagues. Here are a few examples:

- A coordinated stand by international publishers (ICMJE editors) defending evidence-based standards is the commentary in Lancet (co-signed by editors around the world) explicitly denounced the US policies as "part of a global assault on evidence, inclusion, and truth," urging that scientists, publishers and editors "must resist silence" in the face of censorship.[28]
- The nonprofit publisher PLOS (USA/global) issued a forceful blog statement reaffirming its commitment to open, rigorous science.[29]
- In *Nature Medicine*, van Daal et al. explicitly warned that banning words in medical research is "bad news for everyone".[30]
- Other countries' journals and experts have echoed these concerns. For example, an editorial in Tobacco Control (Australia) warned that the new U.S. administration has enacted "savage cuts to health research, agencies and programmes; attempts to prevent, retract or amend scientific publications; [and] deletion of health databases".[31]

Conclusions

Terminology accuracy is essential to provide understandable and meaningful RWE information. Scientists and writers should be free to use all terms that have been developed across disciplines over time and have been demonstrated to be sound and valid for their intended purposes. The loss of that accuracy or the elimination of context-specific terms can deprive decision-makers of vital information.

The recent and continuing censorship policies described this article underlines

- the political vulnerability of health data systems and the implications on global research reliability.
- the need for international standards for data governance and independent audits.

As medical writers and communicators, we are aware that RWE depends fundamentally on the availability, transparency, and integrity of large-scale health data – domains in which the U.S. has historically been a global leader. However, if data is selectively removed, censored, or altered for ideological or political purposes, the very reliability of RWE as a scientific tool is called into question. This not only affects the credibility of US-based data sources but also the trustworthiness of any evidence derived from them. The medical writing community can contribute to safeguarding the ethical use of RWE by building international standards for data governance and independent audits.

Disclaimers

The opinions expressed in this article are the authors' own and not necessarily shared by EMWA. ChatGPT Deep Search was used as a reference tool; each single reference included was verified independently.

Disclosures and Conflicts of Interests

The authors declare no conflict of interest.

Image: Freepik

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