

# Engaging with patients for better treatments and outcomes for smell and taste disorders

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Researchers and patient advocates from the Monell Chemical Senses Center, Smell and Taste Association of North America (STANA), and Thomas Jefferson University came together during the COVID-19

pandemic to incorporate patient voices in efforts to prioritize research areas focused on improving care for people with smell and taste disorders.

To this end, in 2022 these collaborators [conducted a survey and listening sessions](#) with patients, caregivers, and [family members](#) affected by impaired [smell](#) or taste. They asked about their individual perceptions of the effectiveness of treatments, among other topics.

Using an online questionnaire, over 5,800 people in the U.S.—from all 50 states and the District of Columbia—answered the team's call to action. The survey results and critical areas for related research are published in [Chemical Senses](#).

Overall their findings underscore the importance of conducting more large-scale, randomized [clinical trials](#) that include older participants. They also identified a need to parse results among anosmia, hyposmia, and parosmia to better understand the mechanisms underlying each diagnosis.

"Patient voices sound the urgency for [fundamental research](#) on what underlies sensory disorders and how that can be translated into new and better treatments," said senior author Nancy E. Rawson, Ph.D., Monell Executive Vice President & Chief Impact Officer.

The team, which also includes researchers from San Diego State University, analyzed the characteristics that predicted whether [treatment](#) for smell or taste disorders was reported as effective (or not) for patients aged 18–24, 25–39, 40–60 and 60+ years. No treatments were highly effective.

Collectively, the survey participants reported being treated with nasal steroids, oral steroids, zinc, nasal rinse, smell training, theophylline,

platelet rich plasma, and Omega 3. The most consistent predictor of low effectiveness was age. The majority of those 40–60 and 60+ years old reported that nasal steroids, oral steroids, zinc, nasal rinse, and smell training were only slightly effective or not effective at all.

However, many of these treatment strategies target cell regeneration and immune response, functions that can diminish with age. Only those under the age of 40 reported more-than-slight efficacy of steroids or smell training.

"The pandemic and emergence of long COVID uncovered our lack of knowledge of disorders of smell and taste," said first author Claire Murphy, Ph.D., Professor of Psychology at San Diego State University and Adjunct Professor of Psychiatry at the University of California, San Diego.

"The overwhelming response of nearly 6,000 people with smell loss and their family members is indicative of how many people are craving for more information and to be heard."

## **Patient feedback makes a difference**

The survey's age-related data has important implications for clinical trials that measure treatment effectiveness, emphasizing the need to include patients of all ages. In addition, other studies have shown that older adults with olfactory impairment have an increased risk for Alzheimer's disease (AD) and other neurodegenerative disorders.

The authors of the article surmise that olfactory impairment associated with long COVID could lead to a significant rise in AD incidence, making clinical research on new treatments for smell loss a key priority.

The efficacy of nasal steroids and smell training was also influenced by

the type of diagnosis patients received: People with complete loss of smell (anosmia) rated the training less effective than those with a partial loss (hyposmia), and those with a distorted sense of smell (parosmia) rated [nasal steroids](#) less effective than those with hyposmia.

Interestingly, people who were unsure of their diagnosis rated smell training as being less effective than those who were diagnosed with a partial loss of smell.

The authors report that in small-group listening sessions, patients from different survey sub-groups, such as those with complete or partial [smell loss](#), shared individual stories on topics that impacted their day-to-day lives. They expressed:

- A need to know the cause of their disorders and evidence that a particular treatment is effective.
- An interest in smell testing with their [primary care](#) physician.
- An enthusiasm for participating in clinical trials.
- Frustration with treatment strategies that produce little if any benefit and suggesting that new treatments should be tried.

"From the patient survey and listening sessions, we learned that patients have an important and [unique perspective](#) based on their own lived experiences that researchers and clinicians should consider," said co-author Katie Boateng, STANA President. "In particular, patients want to be involved in identifying treatments that directly address impacts on their quality of life."

## **Spurred by a pandemic**

This concerted study of patient-centered approaches to combat smell and taste disorders started with a 2020 white paper that summarized research needs for chemosensory disorders. These details were identified at a 2018 meeting held at the Monell Center with clinicians, researchers, and

patients. Fast forward two years: COVID dramatically changed the awareness of the loss of smell and taste, a principal, early symptom of infection.

Looking forward, the team suggests a number of priorities for future research:

- Developing partnerships among patients, clinicians, and basic scientists to align priorities for research, education, and health care standards.
- Increasing accessibility and use of standardized testing methods for diagnosing smell and taste disorders.
- Clinical studies of emerging therapeutics need to consider a wide range of ages to address changing capacity for regeneration.
- Health care professionals in a wide range of disciplines—from dentistry to nutrition to otolaryngology—need to be provided with training in management of patients with taste and smell disorders.

"These patient voices contributed much to our understanding of olfactory disorders—and their symptoms, diagnoses, treatments, and quality-of-life issues," said co-author Gurston G. Nyquist, MD, Professor of Otolaryngology and Neurological Surgery at Jefferson. "We need to find ways to partner with patients as we plan future research."

**More information:** Claire Murphy et al, Integrating the Patient's Voice into the Research Agenda for Treatment of Chemosensory Disorders, *Chemical Senses* (2024). [DOI: 10.1093/chemse/bjae020](https://doi.org/10.1093/chemse/bjae020)

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