

# Barriers to Effective Healthcare for Patients Who Have Smell or Taste Disorders

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## Abstract

**Objectives:** Smell/taste disturbances are a common but underrated, under-researched and under treated sensory loss and an independent risk factor for reduced longevity. This study aimed to characterise the experience of patients these disorders in seeking help. **Design:** The study was designed by patients together with clinicians through a dedicated workshop and conducted as a cross-sectional survey to capture experiences in public and private healthcare settings internationally. **Setting:** Primary, secondary and tertiary care. **Participants:** Any members of the public self-reporting a smell/taste disorder were invited to participate. **Main outcome measures:** The survey captured information including experience of getting consultations and referrals to medical professionals, treatments offered, costs incurred and related problems with mental health. **Results:** Of 673 participants; 510 female, 160 male, self-reported aetiology included sinonasal disease (24%), idiopathic (24%) and post-viral olfactory dysfunction (22%); true gustatory disorders were typically rare. Failure of medical professionals to recognise the problem was a key concern - 64%, 76% and 47% of GPs, ENT specialists and Neurologists acknowledged respectively. Other issues included repeated ineffective treatments, difficulties getting referrals to secondary/tertiary care, mental health problems (60%) and a mean personal cost of £421 to seeking advice and treatment. Whilst the participants were self-selecting, however they do represent those who are seeking help and intervention for their disorders. **Conclusion:** There is an unmet need for these patients in accessing healthcare including a clear need to improve education of and engagement with the medical profession in Otorhinolaryngology, General Practice and other specialties, in order to remove the current barriers they face.

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# OLFACTORY DISORDERS

The circles show current olfactory abilities of those experiencing some form of olfactory disorder. Many experiences are delineated as false and incomplete. I = Imagined smells, A = actual olfactory perception. (Participant sketches from November 2018, Newcastle-upon-Tyne).



