

Establishing UK Research Priorities In Smell and Taste Disorders: A James Lind Alliance Priority Setting Partnership

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Abstract

Background: A James Lind Alliance Priority Setting Partnership (JLAPSP) was established by Fifth Sense together with UEA to identify the top 10 research questions in the field of smell and taste disorders in the United Kingdom. Methods: After steering group was established, an electronic survey was disseminated to all stakeholders (patients, healthcare professionals, family, carers, researchers) to determine the list of questions. After removing out-of-scope responses, the remainder were consolidated to create summary questions. A literature search was conducted to remove already answered questions. A second survey was used to determine the top questions that formed the subject of final debate at a workshop attended by clinicians and patients to determine the top 10 priorities. Results: The 665 respondents to the initial survey provided 1698 research questions. Thirteen were out-of-scope and removed; remaining 1685 were then consolidated to form 147 summary questions. Following literature search and discussion with the steering group, 37 questions remained for the second survey, which 235 people responded. The top ten priorities agreed in the workshop covered themes of improved understanding of pathophysiology, improving health services, and managing long-term effects of smell/taste disorders. The most important research question agreed was “How can we further our understanding of the mechanism of disease in the nerve pathways that affect smell and taste disorders, including where parosmia and phantosmia exist.” Conclusions: We report the top 10 research priorities in smell and taste disorders. These priorities will now empower researchers to secure research funding and provide the basis of the Fifth Sense research hub.

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