

Fifth Sense James Lind Alliance Priority Setting Partnership for smell and taste disorders



BY NINA BLEASDALE

Research priorities in the past have been dominated by the quixotic curiosity of individual academics and the capricious generosity of funding organisations. There must be a better way...

At Fifth Sense, research is fundamental to the work we do. Above everything else, what people with any health condition seek is a cure or a treatment that works. For people experiencing smell and/or taste disorders, this is no different.

Our Quality of Life survey in 2014 demonstrated clearly how smell/taste loss or disorders impact every day [1].

Whilst there are physical aspects to a disorder such as sinus irritations, nasal polyps and brain injuries to mention a few, there are also the mental, emotional and social health elements to consider. Sixty-one percent of respondents to our survey describe feelings of anxiety and/or depression and 54% feel it impacts on their relationships. All aspects of life affected by a smell or taste disorder are important to address. Fifth Sense have been working on developing a Priority Setting Partnership (PSP) for smell and taste disorders for eight years. Led by Professor Carl Philpott (Director of the UK's first NHS clinic focusing on smell and taste disorders) and supported by funding from the National Lottery Community Fund, the PSP has built on the increased awareness of smell and taste disorders that has resulted from the

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Duncan Boak, Founder and Chair at Fifth Sense and Toto Gronlund, JLA Adviser.

COVID-19 pandemic and provides a unique opportunity to engage patients and their families and friends, as well as the clinicians who support them. Prof Philpott said: *“This partnership will work hard to reach people with a smell or taste disorder – people whose voices are frequently not heard in research.”*

So why is the James Lind Alliance Priority Setting Partnership for Smell and Taste Disorders so important and why have Fifth Sense launched it? The James Lind Alliance (JLA) is a non-profit initiative established in 2004 and is funded by the National Institute for Health Research (NIHR). It brings patients, carers and clinicians together in (PSPs) to identify the top 10 priorities that they agree are the most important to people affected by a particular condition. The aim of this is to make sure that health research funders are aware of the issues that matter most to the people who need to use the research in their everyday lives and so that they can make their research as meaningful as possible to the people who need it.

“I don't think it can be understated just how much smell and taste loss can affect people and the people around them. So anything that can help research and clinical professionals in fully understanding these conditions can only be a good thing.” Ruth Sullivan, a patient member of the Steering Group in the Fifth Sense Smell and Taste Loss PSP.



Chessie Horwood, Fifth Sense Ambassador for Young People and Steering Group Member.

PSPs enable clinicians, patients and carers to work together to identify and prioritise aspects of a condition that could be answered by research.

The Partnerships agree to:

- Bring patient, carer and clinician groups together on an equal footing.
- Identify questions which cannot be answered by existing research.
- Work to jointly prioritise identified uncertainties.
- Produce a final list (often a top 10) of agreed research priorities, publicise them widely, and make sure that other uncertainties are recorded and available for researchers and research funders to access.
- Provide a rare and valuable opportunity for patients and clinicians to shape the health research agenda.

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Duncan Boak, the Founder and Chair, explains: “Fifth Sense has pioneered collaboration to transform the way smell and taste disorders are understood, treated and managed. The PSP builds on the work we’ve done over a number of years and gives us a fantastic opportunity to open up new avenues of patient-focused research, the need for which is even greater following the recognition of smell loss as a symptom of COVID-19.”

On 25 September 2020, the Steering Group came together to participate in the first meeting facilitated by the James Lind Alliance Adviser, Toto Gronlund. Over the ensuing months the survey was developed by the Steering Group and shared across social media networks by partner organisations through press releases and engaging the large community membership at Fifth Sense. The first phase of the survey attracted hundreds of responses that provided thousands of questions and closed on 19 April 2021. The analytic team are busy

finding themes to further investigate prior to the publication of the final priorities in the Autumn of 2021.

For the history buffs... who was James Lind? James Lind was a pioneer of clinical trials. He was born in Edinburgh on 4 October 1716, studied medicine in 1731 and in 1739 he joined the navy as a surgeon’s mate. He was a pioneer of naval hygiene and conducted one of the first ever clinical trials in which he developed the theory that citrus fruits cured scurvy. Lind argued for the health benefits of better ventilation aboard naval ships, the improved cleanliness of sailors’ bodies, clothing and bedding, and below-deck fumigation with sulphur and arsenic. He also proposed that fresh water could be obtained by distilling sea water. His work advanced the practice of preventative medicine and improved nutrition. He died on 13 July 1794 in Gosport. More information can be found in the BBC News article ‘James Lind: The man who helped to cure scurvy with lemons’ [2].

References

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2. White M. James Lind: The man who helped to cure scurvy with lemons. BBC News. 2016 www.bbc.co.uk/news/uk-england-37320399

Both links last accessed May 2021.

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