

SMELL AND TASTE DISORDERS

TOP 10 RESEARCH PRIORITIES AND RESEARCH STRATEGY

This document outlines Fifth Sense's Research Strategy and the key areas of focus for our Research Programme, as developed through our Priority Setting Partnership with input from people affected by smell and taste disorders, their families and healthcare professionals.



DEVELOPING OUR RESEARCH PRIORITIES

In September 2020, Fifth Sense started working with the James Lind Alliance and the University of East Anglia to identify research priorities in the field of smell and taste disorders.

Fifth Sense, the charity for people affected by smell and taste disorders, has worked to engage and involve the people we represent in research since we were established in 2012. Delivering a Priority Setting Partnership (PSP) to establish a set of research priorities had been a key goal since our inception.

In 2020, as the Covid-19 pandemic was at its height and interest in smell and taste research had grown significantly, Fifth Sense successfully applied to the James Lind Alliance to undertake the Smell and Taste Disorders Priority Setting Partnership, supported by our grant from the National Lottery Community Fund.

The PSP involved a number of stages between September 2020 and January 2022:

- A steering group for was established, consisting of a group of stakeholders representing clinical, patient and research domains. It included Ear, Nose and Throat specialists, a Neurologist, General Practitioner, Psychologist and six patient representatives covering the main causation groups for smell and taste disorders. The Steering Group was chaired by an independent JLA Advisor.
- An electronic survey was sent to all stakeholders (patients, healthcare professionals, family, carers, researchers) asking them to submit three uncertainties they wanted answering by future research.
- Independent analysts from the University of E Anglia consolidate the responses, removing out of scope questions, to create a list of summary questions. A literature search was conducted to remove any questions that had already been answered. A second survey was used to determine the top questions from which the final top 10 would be selected.
- A final workshop involving patients, their carers and healthcare professionals was held in Manchester to debate and agree the final top 10 priorities. The workshop was facilitated by independent JLA Advisors.

This report outlines the top 10 research priorities in smell and taste disorders and our research strategy that has been developed in tandem with the PSP. These priorities will support and empower researchers to secure funding and undertake new research. We're looking forward to the journey ahead.

Find out more about the Smell and Taste Disorders PSP and our Research Programme at www.fifthsense.org.uk/research.

If you would like to find out more or get involved then we would love to hear from you. Please contact us at info@fifthsense.org.uk

A huge thanks to our steering group members, data analysts and everyone who participated in our surveys and attended the final workshop.



OUR TOP 10 RESEARCH PRIORITIES

1. 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?
2. How can medical professionals be better educated in treating smell and taste disorders?
3. Do stem cells have the potential to treat smell and taste disorders?
4. How can regeneration of smell receptors be used to treat smell or taste disorders?
5. What are the mental health consequences of smell and taste disorders and how can these be managed effectively?
6. How can medical technology (e.g. implants) be used to rehabilitate sense of smell and taste?
7. How can the testing and investigations into smell and taste disorders be improved?
8. What role does genetics play in smell and taste disorders?
9. Are there any effective treatments for smell and taste disorders due to COVID-19 or any other viral infection?
10. What coping strategies help in dealing with smell and taste disorders?

OUR RESEARCH STRATEGY

The Fifth Sense Research Hub

Our Research Hub has been developed to take forward the outcomes of the Priority Setting Partnership. Split across six core themes, the Hub will engage with researchers and support them to develop and deliver projects that respond to the list of research priorities generated by the PSP. Over time we will grow our research programme and develop funding streams to support it. With our position as the leading charity in this field, our experience in connecting patients, public, clinicians and researchers and our track record of supporting Patient and Public Involvement in Research (PPI), Fifth Sense will act as a key figurehead and driving force for patient-focused research into smell and taste disorders. The Fifth Sense Research Hub will:

- Engage researchers with our priorities and work with them to develop and deliver new research projects
- Attract and engage commercial organisations and funders
- Provide PPI support for research projects via the Fifth Sense PPI Panel
- Act as an entry point for people wishing to participate in research projects or PPI activity
- Engage and involve new audiences in smell and taste research through our engagement, education and outreach activities

Our commitments

- Fifth Sense is a UK-based charity tackling a global problem that requires a global team to address it. We will continue to work collaboratively with individuals and organisations around the world who share our vision, values and ethics to address the challenges faced by people affected by smell and taste disorders through research.
- We will continue to put the people we represent at the heart of our work, engaging and involving them in research through initiatives such as our Public and Patient Involvement panel, Research Champions programme and conferences.
- We recognise that we need to do more to reach and engage with people from black and minority ethnic communities and those who are traditionally harder to reach; whose first language is not English, people living in relatively isolated rural communities and those experiencing severe economic hardship, for example. Smell and taste disorders can affect anyone and everyone. We will follow National Institute of Health Research guidance around inclusion and will develop a research agenda that seeks to engage and involve all.

“We will continue to put the people we represent at the heart of our work...”

- We will work to engage with and support aspiring scientists and early-stage researchers with the aim of growing interest and research in smell and taste disorders.
- We will engage with and support scientists from outside the field to help them translate their ideas and methods with the aim of benefiting people affected by smell and taste disorders.
- We will undertake and support high-quality, ethical research that has successfully completed a peer review process.

If you're a researcher, clinician, technologist or commercial organisation who is interested in working with us to support our goals then we would love to hear from you. Please contact us at info@fifthsense.org.uk



Research Hub Themes and Leads

Our Hub Leads, clinicians and researchers recognised for their expertise in their field, will act as champions for the Fifth Sense Research Hub and support the growth and development of our programme.

BASIC SCIENCE - PATHOPHYSIOLOGY OF DISEASE



Steven Munger Ph.D
Director of the University of Florida
Center for Smell and Taste

STEM CELL & REGENERATIVE RESEARCH



Prof James Schwob
Professor of Developmental,
Molecular & Chemical Biology at
Tufts University School of Medicine



Bradley Goldstein MD
Associate Professor of Head and
Neck Surgery and Communication
Sciences, Duke University School
of Medicine

EDUCATION AND TRAINING



Mr Irfan Syed
Consultant ENT Surgeon,
University Hospital Lewisham



Dr Devina Maru
National Medical Director's Clinical
Fellow, Primary Medical Services
and Integrated Care Directorate,
GP Speciality Registrar, London.



Mr Sankalp Sunkaraneni
Consultant ENT Surgeon,
Royal Surrey County Hospital

CLINICAL TRIALS AND EPIDEMIOLOGY



Prof Carl Philpott
Professor of Rhinology & Olfactology,
University of East Anglia

SUPPORTIVE CARE



Rachel Herz Ph.D
Adjunct Assistant Professor of Psychiatry
and Human Behaviour, Brown University
and part-time Faculty at Boston College



Dr Lorenzo Stafford
Department of
Psychology, University of
Portsmouth

TECHNOLOGY & DIGITAL HEALTH



Marianna Obrist
Professor of Multisensory Interfaces,
University College London

OUTCOME 1

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?



LUCY THOMAS

Lucy lost her sense of smell at the start of the covid 19 pandemic. Parosmia developed a couple of months later and persists 2 years on. Lucy's career depended on her sense of smell so the impact of a long term smell disorder has been devastating.

"It is almost impossible to imagine how devastating a long term smell disorder is. Every part of your life is negatively effected. I hope the outcome of the PSP not only raises awareness of smell and taste disorders but increases the velocity of research and treatment options."



JOANNE DIXON

Joanne lost her sense of smell following a bad cold in 2015 and started to experience horrible distorted smells several months later. No-one, not even her GP, understood the devastating impact of smelling and tasting sewage every second of the day had on her. Joanne was prescribed lots of different types of medication but nothing helped and her mental health suffered as a result. Eventually she was diagnosed with parosmia and tried a course of a drug that made a huge improvement.

"It would make a big difference if GPs were provided with better guidance and information on symptoms and treatment allowing them to refer patients quicker. Smell and taste disorders should be an integral part of ENT research and training and networking with other professionals to widen their knowledge on patient experiences. In the future I'd really like to see dedicated regional Smell and Taste clinics so patients can get access straight away to the right treatment, trial drugs and the support they desperately need."

OUTCOME 2

How can medical professionals be better educated in treating smell / taste disorders?

ADEBAYO ADEGBITE

Bayo is a Community Pharmacist and has hyposmia caused by chronic rhinosinusitis (CRS). He joined Fifth Sense because he would love to be able to smell properly one day.

“I would love medical professionals, especially GPs, to take people with smell and taste disorders seriously and be able to refer them to a nearby specialist smell and taste clinic as soon as possible.”



OUTCOME 3

Do stem cells have the potential to treat smell and taste disorders?



ED SHARDLOW

Ed lost his sense of smell as a result of a head injury. This has had a profound and lasting effect on his quality of life. In the immediate aftermath he immersed himself in getting an understanding of the condition and the impact it has, and discovered a lack of support from the medical profession and little in the way of treatment available.

“While I’ve been able to adapt and reconcile myself to my condition over the years, I still feel the loss deeply and hold out hope for a cure or an effective treatment.”

OUTCOME 4

How can regeneration of smell receptors be used to treat smell or taste disorders?

RUTH SULLIVAN

Ruth lost her sense of smell gradually but has no idea when it all started; her anosmia has no known cause. She had no idea it was even possible to lose the sense of smell so for a long time made up excuses as to why things didn't smell as strongly as they had before. She eventually went to a specialist who told her "well I guess you'll just have to get used to it" and for the next 15 years grappled with overwhelming grief and loss. In 2017 she discovered Fifth Sense and realised that there were many more people in her situation. She described this as an absolute lifeline, and knowing that there are clinicians and scientists wholly dedicated to improving these debilitating disorders as being fantastically affirming.



As a long-term idiopathic anosmia sufferer, the regeneration of smell receptors would appear to be a tangible goal that could really make a significant difference. I often get the sense that odours are just out of reach...could future research finally put smells within my grasp?

OUTCOME 5

What are the mental health consequences of smell and taste disorders and how can these be managed effectively?



DEBS DAVIES

Debs has never been able to smell and was in her 20's before being diagnosed with congenital anosmia. There is no treatment for this very rare invisible condition which impacts daily living, and there was very little information available about it at that time.

It was many more years before Debs was able to learn more and meet other people with it.

"I'd like to see the day when the mental health impact of smell and taste disorders is better understood, where there's greater awareness of this, and where mental health services are routinely available to support people through the myriad of difficulties they face as they adapt to living with their condition."

OUTCOME 6

How can medical technology (e.g implants) be used to rehabilitate sense of smell/taste?

CARL HUGHES

Carl suffered a fractured skull in 2019 and received no information or suggestion that anosmia might well be a side symptom. After his head injuries subsided he noticed and realised very rapidly the reasons why he had been burning the dinner. He says his condition raises so many self-doubts and questions around personal hygiene, whether the gas is still on or the milk has gone off. Carl would like to see devices be developed that could help identify dangerous smells and make the world much safer for people with smell disorders.



"Life has become quite Black and White, keeping it simple has become the normal. Anything that can be done to bring colour back into my life would be a massive bonus"

OUTCOME 7

How can the testing and investigations into smell/taste disorders be improved?



CHESSIE HORWOOD

For a 15-year-old, the testing process to find out Chessie had congenital anosmia was a traumatic experience. It was a year-long experience with little answers or support, with the final appointment outcome being told “that’s it you can’t smell, go live with it”. Through the support of her friends, family and Fifth Sense, Chessie has managed to find out a name for her condition and figured out a way to live in a scent and tasteless world.

“No adult let alone young person should have to go through the testing process without support. Doctors need to be better equipped to able to offer this support and guidance so the journey to finding a diagnosis is not as painful”

OUTCOME 8

What role does genetics play in smell/taste disorders?

KATHY CLUGSTON

Kathy Clugston is a freelance radio presenter. She has been anosmic since birth, but only found out the cause when she made a documentary for Radio 4 about having no sense of smell. A scan revealed she had no olfactory bulb; the reasons for this are unknown. She considers that she has a good sense of taste and is able to distinguish flavours - another mystery.

"I didn't find out that I was congenitally anosmic until I was in my forties. Understanding the genetic elements of anosmia would hopefully lead to greater understanding, earlier diagnosis and better advice to those affected. I would also love to know about any links between anosmia and other conditions associated with smell loss."



OUTCOME 9

Are there any effective treatments for smell and taste disorders due to COVID-19 or any other viral infection?



ELAINE BURLINGHAM

Elaine was diagnosed with anosmia nearly 10 years ago after a severe viral infection. No one in her family or friends had ever heard of anosmia, including her local GP.

“As it was so long ago, no effective treatments were available. Because of COVID-19 there are now things to try including nasal rinsing, smell training and acupuncture. These seem to work for some people with anosmia but not all and what we all need, as a priority, is more research into potential treatments. The second priority is for healthcare professionals to know about smell and taste disorders and to monitor treatments offered to see which may be effective”

OUTCOME 10

What coping strategies help in dealing with smell and taste disorders?

TOM LAUGHTON

Tom lost much of his ability to smell and taste after a random assault on the street when he was 19. He can detect some strong smells, but cannot get the fundamentals that connect us to our lives, such as the smell of his wife, children, or home. The biggest single loss to Tom has been losing so much of his ability to taste.

"I have always loved food and cooking, but as I am unable to perceive so many flavours, I keep my attention on the basic tastes and sensations of food, and the process of cooking. Physical touch with my family is a very important way to replace the connection lost by smell. The contact with Fifth Sense has let me express my reality, be understood, and to grieve a path in life that was lost."



