

Vulnerability & Carbon Monoxide Allowance (VCMA)

Project Eligibility Assessment (PEA)

"Fifth Sense Partnership Programme"

Simon Hames March 2022





Gas Network Vulnerability & Carbon Monoxide Allowance (VCMA) Governance Document - Project Eligibility Criteria

ı oraeı	to qualify as a VCMA project, a project must:	
/CMA	Eligibility Criteria	Criteria Satisfied (Yes/No)
a)	Have a positive, or forecasted positive Social Return on Investment (SROI), including for the gas consumers funding the VCMA project;	Yes
b)	i. Provide support to consumers in vulnerable situations, and relate to energy safeguarding, or ii. Provide awareness on the dangers of CO, or Reduce the risk of harm caused by CO;	Yes
c)	Have defined outcomes and the associated actions to achieve these;	Yes
d)	Go beyond activities that are funded through other price control mechanism(s) or required through licence obligations; and	No
e)	Not be delivered through other external funding sources directly accessed by a GDN, including through other government (national, devolved or local) funding.	No
oroject n order neet th	to qualify as a VCMA project, unsafe pipework and essential gas appliance so e following criteria:	ervicing, repair or replacement must
a)	A GDN has to isolate and condemn unsafe pipework or an essential gas appliance following a supply interruption or as part of its emergency service role;	NA
b)	The household cannot afford to service, repair or replace the unsafe pipework or essential gas appliance; and;	NA
c)	Sufficient funding is not available from other sources (including national, devolved or local government funding) to fund the unsafe pipework or	NA

Section	3 - Eligibility criteria for collaborative VCMA projects	
In order	to qualify as a collaborative VCMA project, a project must:	
a)	Meet the above company specific and boiler repair and replace (if applicable) project eligibility criteria;	NA
b)	Have the potential to benefit consumers on the participating networks; and	NA
c)	Involve two, or more, gas distribution companies.	NA



Gas Network Vulnerability and Carbon Monoxide Allowance (VCMA) Governance Document - Project Registration Table 2

Information Descriped	Description
Information Required	Description
Project Title	Cadent and Fifth Sense Partnership Programme
Funding GDN(s)	Cadent
Role of GDN(s) *For Collaborative VCMA Projects only	NA NA
Date of PEA Submission	10/03/2022
VCMA Project Contact Name, email and Number	Simon Hames Simon.hames@cadentgas.com 07908 898094
Total Cost (£k)	£745,661.48
Total VCMA Funding Required (£k)	£471,300
	Note: the costs are based on a three-year programme at 157,100 a year.
Problem(s)	The Partnership will develop a comprehensive support, safety and wellbeing service for people living with smell and taste disorders including the growing number living with Long Covid symptoms, enabling people to stay safe and well in their own homes.
	There is a need to engage with people and communities who are traditionally harder to reach and therefore may find difficulty in accessing specialist health care services. These include people whose first language is not English, people living in relatively isolated rural communities and those experiencing severe financial hardship. Further, the incidence of smell loss increases with age and people from BAME communities have been disproportionately affected by Covid-19.
	Older people who lose their sense of smell as the result of the ageing process and those who experience smell loss as the result of neurodegenerative diseases such as Parkinson's and Alzhemer's will be an important target group for the programme.
	Fifth Sense's clinical partners provide anecdotal evidence that older people, and their carers, can often be unaware that their sense of smell has deteriorated. This potentially makes them more vulnerable to gas leaks. At least one news report about a gas explosion in recent years where an older person was injured or killed suggested that neighbours were aware of a smell of gas, but that the occupant of the house may not have been ¹ This is an issue that the Partnership will work to tackle, in conjunction with the Fire and Rescue Service, by increasing awareness amongst the wider public that the sense of smell can naturally deteriorate with age, and provide information, resources and tools to ensure people can monitor their sense of smell and take practical steps to keep themselves and their families safe at home, for example the 'scratch and sniff' cards developed by Cadent and Fifth Sense to support people with identifying if they can smell gas.
	There is a growing number of people with Long Covid. Clinical researchers are rapidly learning more about Long Covid and the NHS is undertaking a number of studies. Fifth Sense is a member of a national Long Covid Steering Group and has supported a recent NIHR application led by Prof Carl Philpott. "People of all ages and backgrounds, irrespective of severity of the initial infection, can experience Ongoing Symptomatic Covid-19 and Post COVID-19 Syndrome, also known as Long COVID." Long COVID is described as "a multi-system condition with a wide range of debilitating symptoms" including psychological and cognitive symptoms as well as physical symptoms including loss of smell and taste.
	Research shows the "risk [of major adverse events with Long-COVID] was greater for those who were less than 70 years old and from ethnic minority groups." ³ The study shows that there were some 862,000 people with Long-COVID symptoms after 12 weeks and 321,000 people still affected 12 months after initial infection

https://www.mirror.co.uk/news/uk-news/there-bang-dramatic-scenes-house-11674353
 "Long COVID: The NHS Plan for 2021/22" Version 1, June 2021, PAR C1312.
 http://bmj.com/content/372bmj.n693



and diagnosis. Alarmingly, these numbers will continue to grow as more people have been diagnosed with Covid-19 since the study was conducted.

People living with smell and taste disorders as a result of Long-COVID form a new community within the overall number of people affected by smell and taste disorders. It was suggested (before Long-COVID syndrome) that some 5% of the UK population are affected by smell disorders⁴, which equates to around 3 million people. An estimated 250,000 people have persistent smell and taste disorders resulting from COVID-19. Fifth Sense as a relatively new charity has some 5,000 people on its mailing list after five years.

Through the proposed Partnership, Cadent and Fifth Sense will aim to empower people and enable them to become more self-reliant in self-managing their symptoms thus reducing the burden on the NHS. We will promote safety at home and encourage people with smell and taste disorders to register with the Priority Services Register, promote related products such as the locking cooker valve, become more aware of the dangers of carbon monoxide and the actions they should take to protect their homes, family and friends. The programme will also extend its awareness to include fuel poor and energy efficiency initiatives.

Scope and Objectives

The proposed Partnership between Cadent and Fifth Sense will deliver a pioneering and transformational three year programme of activity around the crucial role that our senses of smell and taste play in our safety, quality of life and wellbeing. Working in alignment with Cadent's Customer Vulnerability Strategy, the programme will enable customers across Cadent's operational areas to stay safe and well in their own homes.

Programme Objective

The key objective is to support people who may be unable to smell gas or smoke and who are therefore found to be in a vulnerable situation as a result. This includes increasing awareness of the fact that the sense of smell can deteriorate with age and with some neurodegenerative diseases, and that individuals or their carers can be unaware of this.

With the support of Cadent, Fifth Sense will establish a number of Information and Support Hubs which focus on support for those with specific smell and taste disorders including:

- a. Congenital anosmia
- b. Post-traumatic olfactory disorders
- c. Post-viral olfactory disorders
- d. Sino-nasal disorders and allergies
- e. Idiopathic olfactory disorders
- f. Qualitative disorders (parosmia and phantosmia)
- g. Taste-specific disorders
- h. Long Covid-related smell and taste loss (the number of patients affected estimated to be around 100,000 in UK at 1 July 2021⁵)
- Older people who experience loss of their sense of smell and taste as the result of the ageing process
- People who experience smell loss as the result of neurodegenerative diseases such as Parkinson's and Alzheimer's

A summary of research findings regarding the number of people affected by anosmia and related disorders is provided in Appendix One along with difficulties and fears common to many people living with anosmia and related disorders.

There are two core strands of activity included in the programme

- The first national smell and taste support and information service linking with the Priority Services
 Register, carbon monoxide awareness and fuel poor and energy efficiency initiatives, as well as
 additional supporting products including the use and distribution of natural gas detectors
- 2. A national engagement and education programme, which will also be open to Cadent employees

⁵ Data derived from US prevalence cited in: "Covid-19 brings Anosmia to the Attention of Psychiatrists", B Schildkrout *et al*, Psychiatric Times, Volume 38, Issue 8, 19 August 2021.



⁴ "Smell and Taste Disorders", NHS University Hospitals, Birmingham, undated, P118_03 Smell and Taste Disorders, downloaded on 23 August 2021 from www.uhb.nhs.uk/Downloads/pdf/PiSmellTasteDisorders.pdf



Strategic development, capacity building and education

With support from the Cadent Partnership, Fifth Sense will develop the first national support, safety and national wellbeing service for people with anosmia and other smell and taste disorders⁶. The national support network will link together telephone support and virtual meetings as well as self-help groups offering formal and informal peer to peer support in each region. As the network reaches out to more people with smell and taste disorders, it will increase awareness and promote the Priority Services Register. In addition, the network will also increase awareness around the dangers of carbon monoxide and support the promotion of fuel poor and energy efficiency initiatives.

With Cadent's support, Fifth Sense will provide the following services:

- Establish the first national smell and taste information and support telephone line
- Provide regular peer to peer support and self-help group meetings in each region (subject to Covid-19 restrictions)
- Develop additional information resources for those with anosmia and other smell and taste disorders (including those linked with Long Covid as a long-term condition caused by the Covid-19 virus)
- Pilot additional online support including 'Ask the Consultant' sessions and opportunities to discuss important issues such as safety in the home, nutrition and healthy eating, and helping a young child with congenital anosmia cope in both the early years and in later years
- Introduce an innovative education programme for health and care professionals to ensure greater awareness of the needs of both children and adults affected by anosmia and other smell and taste disorders.

It is also important to set out what the Partnership will not cover. It will not:

- Promote or sell alternative or holistic therapies that do not have a research-backed evidence base
- Provide individual diagnosis or medical treatment
- Sell or promote commercial products or services, including private clinics

The Partnership will enable Cadent and the charity to be recognised for their commitment to giving practical support and advice to individuals and their families at risk through anosmia and related smell and taste disorders.

With the support of Cadent, Fifth Sense will link with researchers from University College London, University of East Anglia and other institutions to develop proposals for digital sensory technologies aimed at making a measurable difference to the safety and well-being of people affected by impaired smell and taste.

Further, Fifth Sense will undertake the first national survey of smell and taste disorders. This will help to establish the number of people affected by these hidden disorders, how they affect people at different ages and from different backgrounds as well as the impact of the conditions on quality of life including mental well-being. The Cadent partnership will support this major study.

Through the Partnership, Fifth Sense will support Cadent in developing a colleague and extended operational partner training programme to provide an overall awareness of anosmia, related safety issues and how the business can work to continually safeguard customers and others by taking appropriate actions. The training programme will be delivered through a blend or face-face and online content. The programme will become an annual training model completion requirement.

In addition, staff at Cadent and its wider operational partner network will be offered opportunities for education and personal development. These will include experiential learning through training sessions based on smell testing and rehabilitation using carefully selected fragrances and also food and nutrition workshops. The sessions will also look at the causes of smell and taste loss, safety issues, impact on quality of life, current treatments and an overview of current research.

Cadent staff who have undertaken an initial training course would be invited to become Smell and Taste Champions in their own communities. They can volunteer to join Fifth Sense to 'meet and greet' people

³ "Following treatment, I am able to smell again much of the time I can smell gas, if the burner on the stove didn't turn on correctly, or paint, if a hallway is newly painted. I can smell if milk has gone sour. If I can smell these things I can protect myself from them better." Reported by patient and cited in "Barriers to effective health care for patients who have smell or taste disorders", S Ball *et al*, Clinical Otolaryngology, 4 June 2021





attending a Smell and Taste Roadshow event in a local shopping centre or at food festivals and similar events.

Cadent staff will be able to take part in fundraising activities to support Fifth Sense; these can range from events such as running, cycling and swimming which promote fitness and health as well as fun activities such as cake making, 'dress up Fridays', quiz nights and a 'Fifth Sense Dinner and Auction'. We can tailor any of these activities to the interests of the staff team and we can also support members of the team in any fun challenges or events they want to undertake themselves. There are potential benefits in terms of personal development and in team building for members of the Cadent staff team.

Working with Cadent's support, Fifth Sense will reach more people affected by anosmia and other smell and taste disorders. There will be more support for them and their families and Fifth Sense will encourage greater self-management of their condition.

A marketing and communications strategy will be developed to help increase the reach of the programme, share successes and disseminate findings. Target audiences will include clinicians and their professional bodies, such as the Royal Colleges, relevant 3rd sector organisations and national and local press. Presentations at the Ofgem Annual Showcase event will be an opportunity to share the success of the programme and engage other potential partners such as the other GDNs and fire and rescue services.

Education, training and professional development

The education strand of the first year of our programme will focus on providing general information on the impact of anosmia and related smell and taste disorders and improving help and support for children and adults. The programme will develop specific learning materials and resources for groups of relevant professionals to enable them to:

- a) benefit from having their knowledge in this area enhanced so they can better support people they encounter in their roles
- b) be able to act as advocates in clinic settings for the support provided by Fifth Sense, helping the charity to reach and support more people.

There is currently no such educational programme running in the UK. This is seen as a huge opportunity to deliver pilots which will increase awareness and knowledge across a broad professional spectrum and may develop into funded programmes and also lead to further opportunities for collaboration and research.

We plan to deliver pilots with each group in year one and undertake evaluation to measure success and identify demand for further education/training programmes. The National Director would then look to secure further funding to support delivery of any pilots which have potential to become programmes.

Audience	Rationale	Target for pilot work
Cadent employees	Cadent gas engineers: Provide understanding, awareness and tools to safeguard people affected by a smell or taste impairment. Use of 'scratch and sniff cards' and promotion of the natural gas detectors Delivered by a blend of face to face training and online content. Pilot to concentrate on North London network as a result of the high concentration of multi occupancy buildings, which create a high-risk environment due to the concentration of customers in one building. In addition, London had a high concentration of Covid cases and therefore long Covid may be more prevalent	100 – pilot North London network with an initial group of engineers with a view to rollout to remaining engineers 2022/23
Fire and rescue service	Being unable to smell gas and smoke presents a significant safety risk for people. Fifth Sense will work with the FRS to make them better aware of the safety and wellbeing issues associated with an impaired sense of smell, and also the fear and worry that people experience as a result. The goal is to equip FRS staff with the awareness and tools to better support people with impaired smell and taste when carrying out their Safe and Well visits.	Initial pilot sessions for FRS staff in priority geographical areas (I.e. high incidence of long covid)



		Link to Cadent's use of 'scratch and sniff cards' and promotion of the natural gas detectors.	
Mind - Adv	isor team i	Smell/taste disorders can cause significant quality of life impact on those affected and depression and anxiety are common. Discussions with the Head of Service at Mind in January 2021 identified an opportunity to deliver education sessions to the Mind advisory team to help them become better able to support people affected by smell and taste impairment. Smell/taste impairment is quite common in people who	Initial pilot sessions for c30 Mind Advisors (to be discussed with Head of Service at Mind) Initial pilot sessions for
team		have suffered TBI but the brain injury professional community is still learning about this. FS have established a relationship with the Headway leadership team and Headway have run a number of articles about smell loss following TBI. There is an opportunity to build on this and deliver educational sessions for their staff and volunteers.	60 Headway staff/volunteers (to be discussed with Headway team)
GPs and h professions community	als in the	Many people affected by anosmia and other smell and taste disorders report a lack of understanding by their GP leading to delays to seeing a consultant. The 'diagnostic odyssey' can be both stressful and costly in its impact on mental health and other aspects of the patient's life. We will develop links with the Royal College of General Practitioners, the Royal College of Nursing and other professional bodies.	Professional development in an initial 6 GPs 'Protected Learning Time' sessions. Also 2 articles for GP-focused journals (including British Journal of General Practice and Pulse magazine) and a Fifth Sense presence at RCGP national Conference.
Consultant ENT teams	5 1 5 6 1	Located in secondary and tertiary health care settings, ENT consultants provide specialist services (including surgery, where appropriate) for patients presenting with anosmia and other smell and taste disorders. We will further develop our links with ENT UK and the British Rhinological Society	Development programme with an initial 6 sessions led by trained patient volunteers, 2 articles in journals and presence at one Conference.
Counselling Psychiatry	1 (<u>8</u> 1	The covid-19 pandemic has increased awareness of the mental health impact of smell and taste disorders in the Psychiatry world (https://www.psychiatrictimes.com/view/covid-19-brings-anosmia-to-the-attention-of-psychiatrists). It feels like now is the time to build on this and give Counsellors and Psychiatrists the opportunity to increase their knowledge in this area.	Offer to deliver a pilot session for c30 members of the British Association for Counselling and Psychiatry
Dietetics	i 6 1 1	Fifth Sense has delivered several webinars on the impact of smell and taste disorders with a focus on eating and nutrition in partnership with a registered dietician and has links with several others working in this field. As above, there may be an opportunity to build on this and deliver education	Offer to deliver a pilot session for c30 members of the British Dietetic Association
Schools ar community with SAPH	nurses a	Will improve understanding and awareness in schools and the community working with SAPHNA (Schools and Public Health Nurses Association). Children with congenital anosmia (and their families) need care and support as they come to terms with 'being different' from friends and classmates.	To train 12 volunteers to deliver in year one 24 learning events for school nurses, community nurses and health visitors

Extending the reach of the Cadent Partnership to patients and families across Britain

Further, after the initial 12 months, there would be potential to explore extending the Strategic Partnership with Cadent to other GDNs to ensure people with smell and taste disorders in regions not served by Cadent do not feel they are missing out on the excellent benefits the proposed Partnership will bring to Cadent's customers. The partnership established by Cadent and Fifth Sense in the first full year will be a blueprint for a model to be offered to the other companies.

Programme Organisation



As the work and impact of Fifth Sense is growing, a key post of National Director will be established to drive the strategic development of Fifth Sense. Subject to funds, the Partnership will also support a new role of Education Office (part time) and two posts of Information Support Officer to enable the ambitious Cadent Partnership work programme to be delivered.

The responsibilities of the National Director will include:

- Work directly to ensure the success of the Cadent Partnership, oversee all aspects of the contribution to be made by Fifth Sense and ensure targets are met by Fifth Sense
- Ensure leadership, good governance and strict financial controls are in place and guide the development of the education programme to enable people unfamiliar with smell and taste disorders to learn about their impact, potential treatments and steps to include effective cures
- Build the profile and work of Fifth Sense with medical practitioners and those in related professions including the smell, taste and fragrance industries
- Establish a 'reach and engagement' strategy to ensure people diagnosed with smell and taste
 disorders and their families know about the work of Fifth Sense and can meet and talk to others with
 a similar condition; this can be online and also at face-to-face peer support meetings (with safety
 measures in place, post-Pandemic)
- Develop the communications strategy for Fifth Sense including a 'reach and engagement' strategy
 to identify and support people living with anosmia and other smell and taste disorders; further, a
 media and contacts plan will be put in place to communicate the needs of those affected by smell
 and taste disorders in the media and with ministers and senior officials in government

The proposed staff structure to deliver the partnership programme is attached as Appendix Thee. The organisation chart also shows the posts supported through an existing grant from the National Lottery Community Fund. This grant runs for three years.

Customer Reach

Fifth Sense will deliver a transformational programme to address the safety and wellbeing issues for Cadent's customers living with anosmia and related smell and taste disorders. Fifth Sense as a relatively young charity reaches today some 5,000 people across the country. We anticipate we can grow this number to 75,000 people through the full range of activities set out in this plan.

In the longer term, Fifth Sense intends to embed the services to be introduced through the Cadent Partnership as core activities for the charity (along with the Research programme currently under development). It will be a key priority for the National Director to ensure Fifth Sense has a sustainable, long term funding model in place by developing several income streams during the term of the Cadent partnership.

Why the Project is Being Funded Through the VCMA

The Cadent and Fifth Sense Partnership Programme will focus on identifying and supporting customers in vulnerable situations as a result of suffering from permanent or temporary anosmia. The aim is to ensure customers and the communities they live in remain safe and free from gas incidents.

Cadent and Fifth Sense will work together to create a bespoke programme creating awareness and action driven communication channels that include:

- National smell and taste support and information
- An engagement and education programme

The table below describes the services that will be promoted to increase awareness of as part of this programme, and how this links into the commitments Cadent have made for RIIO-2, as part of our Customer Vulnerability Strategy:

Energy Safeguarding Service to be promoted

PSR awareness including alternative contact options, safety, communication and accessibility

Energy efficiency and fuel poverty

CO Safety

Additional safeguarding products such as natural gas detector awareness and distribution



	This will be embedded within a wider programme of work with core outcomes on addressing anosmia related issues and associated supporting actions.
	The programme will also provide opportunities to explore innovative supporting solutions, the funding mechanism will be decided at a later date (i.e. Innovation fund or increased VCMA)
Evidence of Stakeholder/Customer Support	A key evidence point was establishing the risk of being impacted by a gas incident for people living with anosmia. To establish this, a survey facilitated by Fifth Sense and in conjunction with Anosmia Awareness Day 17/02/2022 was carried out. The survey included a number of questions with the focus being on gas safety concerns, scares and incidents and there were 230 respondents. The results of survey are as follows:
	 Q10 captures how many people are concerned about safety – 87% of which were with 7% having not thought about it until now – part of the reason we asked this was because the fact that our sense of smell plays an important 'early-warning' role isn't obvious to many people, even after they have a problem with their sense of smellwe know this from anecdotal evidence from Fifth Sense members. We believe this figure could well be higher if we surveyed a wider cross-section of the general public. Q11 captures the types of concerns people have, and how much they are concerned – Just under 90% of respondents are concerned about gas safety specifically. Q12 – the numbers of gas safety scares - 46% have had at least one safety scare, with quite a lot having multiple Q13 – gas safety incidents – 17% of respondents have had at least 1 gas safety incident in the past 5 years.
	The survey results included written customer responses, these included:
	"When smart meters were being fitted for electricity and gas, our gas had to be turned off until a very small leak from our gas fire was fixed. It is possible that in the past, before anosmia struck, I would have been able to smell the gas leak. However, my husband hadn't smelled the leak either, and his sense of smell is normal."
	"I was cleaning the stove and didn't realize I turned the dial. I was playing music at home too so I didn't hear the hiss right away. After some time of walking around the kitchen/living area, I hear the hiss. I followed the sound and realized the gas knob was turned and was making the hiss. I didn't smell the gas at all. I turned it off and opened the windows and ceased all activity since no one else was at home to tell me how much the apartment smelled like gas. It was probably 5 - 10 minutes on."
	 "My gas scare safety was more than five years ago, but was very serious. Building works next door had caused earth movements, cracking the gas main. A neighbour knocked on the door wondering why I hadn't reported it, not knowing me as I was new to the area, and she was trying to be respectful. The gas company arrived within 15 minutes, and shut the gas to the entire street, it was apparently a very big leak"
	"It is a constant worry following our move to a house with a gas cooker. My mother suffered from Alzheimer's and lived with us. On a couple of occasions she left the gas cooker on unlit. Having no sense of smell our dog alerted me to something being wrong but even though I went in the kitchen I was not aware what it was. I returned to the lounge but the dog again barked at me and then in my face, with his paws on my knees. I called my young daughter and we followed the dog into the kitchen. My daughter screamed out as she realised the level of gas in the kitchen and we opened all the windows and back door. It was a very close call for our family. Thank god for the dog."
	The survey results are detailed in Appendix One of this document. Appendix One also included further evidence provided by Fifth Sense in support of this paper.
Information Required	Description
Outcomes, Associated Actions and Success Criteria	Fifth Sense will deliver the programme through two core strands of activity: The first national smell and taste support and information service linking with the Priority Services Register, carbon monoxide awareness and fuel poor and energy efficiency initiatives. An engagement and education programme, open to all Cadent employees
	The strategic outcomes of the programme are as follows:
i .	



Outcome	Relevant programme strand(s)	How this outcome will be delivered
Increase awareness of PSR Register	National Support and Information Service, Engagement and Education programme	 Signpost all support and information service uses to PSR Register (embedding within call handling script, giving out information at support sessions) PSR conversations and leaflets given out at Smell and Taste Roadshows. Information about PSR provided in all virtual sessions
Enabling people with a poor or no sense of smell (anosmia), including those in harder to reach groups, to live safely and well at home	National Support and Information Service, Engagement and Education programme, Research Hub	 Provide people with resources and information to help them live safely and well with a smell or taste disorder Signposting people to free/low cost natural gas detectors Reach and engagement activities with harder to reach groups and specific ethnic communities Working with researchers to develop technologies to help vulnerable people affected by smell and taste loss to live safely at home
To help people stay safe at home through increasing awareness that the sense of smell can deteriorate with age and neurodegenerative disease	National Support and Information Service, Engagement and Education programme, Research Hub	Develop and disseminate information resources aimed at older people to increase awareness of age-related smell loss Disseminate these resources via the Engagement and Education programme Facilitate and initiate research that seeks to explore this issue further and find solutions to help people stay safe at home
Educate intermediaries who can in turn reach and engage more people with a smell or taste disorder	Engagement and Education programme,	Establish a pioneering national education/training programme delivered to key audiences including Cadent staff, Fire and Rescue Service, healthcare professionals and relevant 3 rd sector organisations
In addition to anosmia related activities, Increase awareness of the dangers of carbon monoxide (CO)	National Support and Information Service, Engagement and Education programme	 Signpost all support and information service users to CO advise (embedding within call handling script, giving out information at support sessions) CO conversations and leaflets given out at Smell and Taste Roadshows. Information about CO provided in all virtual sessions Include children awareness education through Cadent's Safety Seymour and CO Crew initiatives
In addition to anosmia related activities, support Cadent in increasing awareness of the Fuel Poor and Energy Efficiency initiatives	National Support and Information Service, Engagement and Education programme	Signpost all support and information service users to Fuel Poor and Energy Efficiency advise organisations and information (embedding within call handling script, giving out information at support sessions) Fuel Poor and Energy Efficiency conversations and leaflets given out at Smell and Taste Roadshows. Information about Fuel Poor and Energy Efficiency provided in all virtual sessions

Measuring Success

In measuring the success and impact of the Cadent partnership, the Social Return on Investment will assess the increase in the reach of Fifth Sense within the patient community. The lockdown and inability to hold face to face gatherings has slowed progress in recruiting volunteers and supporters in 2020-21. However, the Cadent Partnership will enable Fifth Sense to achieve a significant year on year increase in people with anosmia and related smell and taste disorders engaging with Fifth Sense and our information and support service.



Year	Increase in people receiving direct support from Fifth Sense	Increase in people reached through engagement programme	Number of staff from external organisations receiving education/training	Cadent colleagues receiving education/training	Cadent operational partners receiving education / training
2022	5,000	7,500	450	1449	200
2023	7,500	15,000	600	3001	600
2024	10,000	30,000	750		
Total	22,500	52,500	1,800	4,500	800

At the end of three years, the partnership will have:

- Provided direct support to an additional 22,500 people, including within harder to reach communities
- Reached out to 52,500 people, many with Long Covid symptoms including anosmia
- Delivered training and education programmes to 1,800 people as intermediaries
- Developing and delivering a structured experiential education and training programme for 4500 Cadent colleagues (engineers), a extend this to its operational partners:
 - o increase their understanding of the crucial role that our senses of smell and taste play in our quality of life, wellbeing and safety, the impact of smell and taste disorders and what can be done to help those affected
 - enable them to pass on their learning to others, including Cadent's customer base through employee's day to day work for the company, and also people in employees' local communities via a Fifth Sense-led Smell and Taste Champion scheme
- 100% of conversations will raise awareness of the PSR to support people who find themselves in a vulnerable situation and facing higher risk through anosmia
- 100% of PSR conversations will include raising awareness of the importance of having an alternative contact added to the PSR
- In addition to anosmia related activities, support Cadent in increasing awareness of the dangers of carbon monoxide (CO)
- In addition to anosmia related activities, support Cadent in increasing awareness of the Fuel Poor and Energy Efficiency initiatives such as reduced energy bills, Warm Home Discount and energy safeguarding services
- Engaged Cadent's Innovation Team in the Fifth Sense Research Strategy and identified future opportunities and put links in place between Cadent's Innovation team and University-based researchers developing multisensory devices and interfaces

Outline Programme Timeline and Activity Summary

	Year 1	Year 2	Year 3
National Support and Information Service to build close links with Cadent's staff. including engineers, and link with the Priority Services Register, CO awareness and fuel poor / energy efficiency initiatives	Telephone information line launched Launch pilot face-to-face and virtual support sessions in Cadent operational areas with identified needs, i.e. high incidence of long covid Start scoping opportunities/needs amongst specific harder to reach groups, ethnic communities, older people	 Ongoing delivery of telephone service Establish programme of support sessions based on evaluation data from year one Deliver pilot sessions tailored to needs of specific communities 	Ongoing delivery of telephone service To have established a programme of face-to-face/virtual support programme, including sessions tailored for specific communities
Engagement and Education programme to engage Cadent's staff, other professionals and	 Work with Cadent to develop training/education framework tailored to needs of its different colleague and operational partner groups and deliver 	 Roll out Cadent training programme across remaining networks. Mandatory compliance CBT delivered 	 Sustain / enhance Cadent training programme To have established a set



	external	pilot plus rollout fully	Launch pilot 'Smell and	training/education
	organisations	across North London Network Develop and deliver pilot sessions for key clinical groups, 3 rd sector organisations, Fire and Rescue Service Deliver pilot 'Smell and Taste Roadshow' public engagement activity in 2-3 shopping centres in Cadent operational areas	Taste' Champions initiative with Cadent staff Roll out small-scale clinical education programme based on evaluation data from Y1 pilots Scale up 'Smell and Taste Roadshow' public enactivity Trial having a stand for the Partnership at some relevant major public events/festivals, i.e. science festivals, BBC Good Food Show. Explore piloting the above initiatives for other GDNs	programme and Smell and Taste Champions scheme for Cadent staff that can continue to be delivered annually • To have established an 'intermediaries' education/training programme • To have established a national Smell and Taste public engagement programme • Be in a position to roll out activities into other GDN regions, and potentially deliver training and education to other Utility companies
	Fundraising to ensure sustainability of Cadent Partnership projects and outcomes	Develop and implement fundraising strategy that will have long-term sustainability of the programme at its core. This will incorporate a number of revenue strands including grants, beneficiary-led fundraising activity, corporate giving and others Identify any appropriate opportunities for Cadent staff to support Fifth Sense fundraising	Use successful outcomes from Year 1 pilots to support grant applications to bring in additional funding to support Engagement and Education activity Ensure fundraising is embedded across Engagement and Education workstream activities, i.e. fundraising at S&T Roadshows Undertake fundraising activities with Cadent staff	National Director to ensure that a funded plan is in place to support all strands of the programme beyond the end of the three year Cadent-funded period, potentially supported by other GDNs and other Utility companies
	Marketing and communications	 programme. This will include: Media/press activity Presenting at Ofgem annual Regular communications ab Sense channels, including it Targeted communications for 	out the programme to go out thro	ough exisiting Fifth
Project Partners and	Fifth Sense - Prima	ary Partner		

Third Parties Involved

Cadent will be working in partnership with Fifth Sense who are a charity governed by a Board of Trustees (see Appendix Two). Fifth Sense's aims to address the lack of understanding within society of the role that the senses of smell and taste play in our lives, a major reason for the lack of appreciation of the impact that disorders of these senses can have on those affected.

Fifth sense aim to play a leading role in educating society on the importance of the senses of smell and taste to our lives. Through this they can: engender better awareness of the serious consequences of smell and taste disorders; demonstrate the need for better education amongst the medical profession; lobby for greater availability of medical services and pursue the need for further research into such conditions and their treatment.



Fifth Sense is a register charity (charity number 1175553) and a company limited by guarantee (company number 10255303)

Fifth Sense has experience of managing a major national programme through the three-year grant from the National Lottery Community Fund secured in 2019. The programme is well

Fifth sense will engage with the following third parties to design and deliver the programme:

Fire and Rescue Service

GPs and community health professionals

Mind - mental health charity in England and Wales

Headway - charity focused on brain injury

ENT Teams - ENT consultants provide specialist services (including surgery, where appropriate) for patients presenting with anosmia and other smell and taste disorders.

Counselling and Psychiatry - British Association for Counselling and Psychiatry

British Dietetic Association - professional association and trade union for dietitians in the United Kingdom.

Schools and Public Health Nurses Association - professional organisation dedicated to the promotion of excellence in practice, taking forward the public health agenda by working in partnerships for the benefit of children and young people and the communities where they live and learn

James Lind Alliance (University College London) - The <u>James Lind Alliance (JLA)</u> is a non-profit making initiative established in 2004. Aim 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.

Potential for New Learning

Cadent have made a commitment to have 2 million direct conversations to raise awareness of the PSR during the RIIO-2 period. Therefore, the conversations that take place via the direct support , engagement programme and education programme as part of this programme will not only contribute towards the 2 million, but will also allow our engineers to arrive at those properties fully informed, knowing how they can adapt their actions accordingly, to benefit the needs of the household.

Currently a minimal number of customers registered on the PSR have an additional contact listed, therefore we can use this opportunity to highlight the importance of a customer listing a trusted person as an additional contact.

Cadent will be able to have a greater knowledge of where people have anosmia within networks.

Cadent colleagues will gain a greater understanding of the anosmia and how its effects impact people lives and what actions should be taken to ensure they remain safe as well as the communities they live in from gas related incidents.

As the programme progresses there will be further learning opportunities available through innovation initiatives

Scale of VCMA Project and SROI Calculations

The programme funding with be for a 3 year period and total £471.3k and breaks down as follows:

	Year 1	Year 2	Year 3
National Support and Information Service	£79.6k	£79.6k	£79.6k
Engagement and Education Programme	77.5k	77.5k	77.5k
Total	£157.1k	£157.1k	£157.1k

An independent SROI assessment has been undertaken by SIA Partners which has resulted in a positive return as follows:

National Support and Information Service

5-year SROI Results				
Total cost £377,417.07				
Total gross present value	£5,736,628.41			
NPV	£5,359,211.33			
SROI	£14.20			





Engagement and Education Programme 5-Year Benefit Breakdown 5-year SROI Results £368,244.41 Total cost Total gross present value £2,636,427.28 £2.268.182.87 NPV SROI £6.16 ■Financial ■Health & Safety ■PSR & wider services **Detailed SROI results including assumptions:** Cadent Fifth Sense SROI Results v1.0.pdf **VCMA Project Start** April 2022 - April 2025 and End Date Geographical Area By the end of the programme the aim is to embed working practices across all Cadent Networks. A training programme pilot will initially take place in North London network due to the high number of Covid infections and potential for long Covid as a result. As there is also a high concentration of multi occupancy buildings the anosmia related risk is naturally higher due to population density. The smell and taste support and information service will be national There will be an opportunity to rollout the Cadent Fifth Sense Partnership blueprint across other GDNs which in turn would indirectly extend the overall geographical reach. This will be dependent on successful piloting and GDN funding support. Remaining Amount in Remaining funding left in the Licensee's/Licensees' funding pot. the Allowance at Time of Registration



Gas Network Vulnerability and Carbon Monoxide Allowance (VCMA) Governance Document - PEA Control Table

In order to ensure that a VCMA project is registered in accordance with the Ofgem VCMA governance document (incl. project eligibility assessment), the below table should be completed as part of the project registration process.	
Stage 1: Sustainability and Social Purpose Team PEA Peer Review	
Date Immediate Team Peer Review Completed: 01/12/2021	Review Completed By: Jo Giles
Stage 2: Sustainability and Social Purpose Team Management Review:	
Date Management Review Completed: 01/02/2022	Review Completed By: Gemma Norton
Step 3: Director of Sustainability and Social Purpose Sign-Off	
Director of Sustainability and Social Purpose Sign-Off Date: 10/03/2022	
Step 4: Upload PEA Document to the Website & Notification Email Sent to Ofgem (vcma@ofgem.gov.uk)	
Date that PEA Document Uploaded to the Website: March 2022	
Date that Notification Email Sent to Ofgem: March 2022	



Appendix One

Fifth Sense Anosmia Awareness Survey Results









Q10 Safety Concerns Q11 What concerns 040322.pdf you 040322.pdf

Q12 Gas safety scares.pdf Q13 Gas safety incidents 040322.pdf

Evidence of Need from (i) Published scientific and clinical papers and (ii) Fifth Sense patient data

Loss of smell is a common complaint in adults. The overall prevalence of olfactory disorders varies between 1 and 20% according to different European population surveys, with anosmia, complete loss of smell, thought to affect at least 1% of the population.

Data on absolute numbers of UK sufferers is lacking; largely due to under-reporting by patients, GPs and ENT Specialists, exacerbated by a lack of coding needed for NHS data.

Chronic rhinosinusitis (CRS) is estimated to affect 10% of the UK population and at least 1% of the population seek a GP consultation every year with 120,000 related ENT outpatient consultations and 40,000 operations for sinus surgery in England and Wales. Loss of smell is one of the diagnostic symptoms of CRS and highlighted as a frequently dismissed symptom by sufferers. Sinus disease is the commonest cause of smell loss seen in a secondary care setting. Loss of smell due to viral damage and head injury remain the two second most common causes.

In March 2017, the official journal of the International Rhinologic Society published a position paper on olfactory dysfunction, citing figures on prevalence that varied widely with survey design.

However, it is clear that prevalence increases sharply with age, with reported incidence as high as 40% for over-65s and over 60% for over-80s. The paper notes that "the sense of smell remains relatively poorly researched and is often neglected by the medical community", and that "there is increasing evidence that olfactory impairment can affect quality of life, through environmental and social anxiety, food and weight disturbances and depression. Moreover, a growing body of evidence connects olfaction to major health outcomes, including neurodegenerative disease and death." ⁷

From the information gathered by Fifth Sense from our own members it is clear that smell and taste disorders have a massive impact on people's lives. In 2014 Fifth Sense carried out the first UK survey of people living with smell and taste disorders in collaboration with the University of East Anglia. Key findings from 496 respondents were that:

- patients with olfactory loss (of all causes) report high rates of depression (49%) and anxiety (47%). This compares to rates
 of depression of 8-12% amongst the general UK population 8
- 92% experienced reduced appreciation of food and drink due to a loss of flavour perception which can adversely affect their appetite, but this can be made even worse if distortions of the sense of smell (such as parosmia) co-exist (67% of Post-Viral Olfactory Loss sufferers). There do not appear to be comparable data for the general population
- 85% experienced exposure to dangers such as gas and rotten food; again, do not appear to be any comparable data for the general population
- Between 56% and 76% experienced emotional difficulties such as anger, frustration, stress and isolation; do not appear to be any comparable data for general population

Comments from people living with anosmia included:

- "Life ... is full of odours and tastes that make us aware of dangers and delight. This has been removed from me and my life."
- "When I was told my anosmia was permanent, the doctor who told me became very embarrassed and possibly threatened by my reaction and actually told me that I should consider myself lucky it wasn't my sight. It's over 9 years later and I am still very angry at the medical response."
- "Above all smell is the sense which makes reality different from a highly sophisticated TV facsimile. Its absence thereby gives a feeling of isolation as well as depriving one of a myriad of pleasures, and, as I have personally experienced following a gas escape, can put one and others in very dangerous situations."
- "I lost my sense of smell 34 years ago. I have still not come to terms with it. I remember what pleasure and learning I got through smelling things. I used to be an avid cook and perfumes were a serious interest. Because it is an invisible disability, most people do not know I have it and do not understand."

⁷ Published in Rhinology, VOLUME 54, Supplement 26, March 2017

^{8 &}quot;Psychiatric morbidity among adults living in private households", Singleton et al, 2003



The survey concluded that "there is a significant and previously unquantified problem with those affected in many ways from professional to emotional and nutritional issues. However, there is also a greater problem of the understanding of the role the sense of smell plays in everyday lives, both in the general public and among the medical profession." ⁹

Scientific papers arising from this study included a paper published by the Royal College of Surgeons in 2014, which noted that "olfactory dysfunction is common, affecting 1–5% of those under the age of 60 and at least 20% of those aged more than 60 years. In many UK centres, the approach to it is variable and routine olfactory testing is not performed, as noted by a recent survey of British ENT surgeons. This is in contrast to Europe and the USA, where many specialist smell and taste centres already exist." ¹⁰

In an interview published on the Fifth Sense website in May 2018, neuroscientist and psychologist Dr Rachel Herz highlights in particular how smell impacts on mood, sexual attraction and personal relationships.

In 2016 Fifth Sense carried out a more solution-focused member survey, with 596 responses. Key findings included:

- The most commonly reported symptom was complete anosmia (77%)
- 60% said their condition had lasted for 5 years or more
- 88% had sought medical advice. Of these 71% had found it unhelpful, and a further 22% were unsure. Only 7% had definitely found it helpful.

In 2020 a research paper based on a project undertaken by Fifth Sense, 'Barriers to effective health care for patients who have smell or taste disorders' revealed alarming facts about the poor levels of understanding and care of smell and taste disorders experienced by many patients.

The findings, captured via a major survey undertaken by Fifth Sense and completed by over 600 patients, highlight the difficulties that people with smell and taste disorders experience in accessing treatment.

- More than one-third of GPs and more than half of neurologists failed to recognise an impaired sense of smell or taste as being a problem for the patient
- More than 60% of patients in the study reported suffering from anxiety or depression
- Some 98% of patients said their quality of life had been affected
- Alarmingly, only around 20% of patients reported in the survey that they had experienced an improvement in their symptoms following treatment

The survey captured the poor experiences of patients when accessing healthcare for their smell and taste disorder. It also highlighted the poor level of understanding of the impact of smell and taste disorders on patients by many GPs and consultants.

The survey identified many areas that were consistent across multiple experiences, including:

- Knowledge of appropriate treatments is often lacking amongst medical professionals, leading to no treatment or repeated ineffective treatments being prescribed.
- Obtaining a specialist consultation is a challenge for many patients, with 1 in 4 reporting a difficulty in getting a referral.
- The clear impact that smell and taste impairment can have on mental health. There are many reasons why this could be
 the case, including the loss of quality of life and also the fact that smell and taste have clear connections to important
 emotional parts of our brains.

Appendix Two

Short biographies of the Trustees of Fifth Sense

- Professor Carl Philpott is Professor of Rhinology and Olfactology, Norwich Medical School, University of East Anglia. Also Honorary Consultant ENT Surgeon & Rhinologist, Norfolk & Waveney ENT Service, Director of Medical and Research Affairs
- Azim Karimjee is an engineer by training who has held several senior positions in the
 commercial sector. He was Finance Director of Prologic Ltd on his retirement in
 February 2019. In addition to his role as a Trustee and the Treasurer of Fifth Sense,
 Azim is a school governor and Principal of the EPS Partnership which focuses on
 helping ambitious SMEs develop and grow
- Esther Kirby is a Registered Nurse with more than three decades of working in health care. She was a Chief Nurse in the NHS before retiring in 2018. Esther is a Kings Fund Top Managers Programme Alumna and also worked in health education

⁹ Published in Chemical Senses 39: 711-718, 2014

¹⁰ In Annals of Royal College of Surgeons of England (Suppl) 2014; 96: 156-159



transformation at Health Education England. She has been recognised as a Queens Nurse (QNI) for her work and achievements in community nursing

- Robert Meadowcroft brings expertise in leading and managing health charities, organisational development and community engagement. He was a Director and then Chief Executive of Muscular Dystrophy UK for 12 years after several years leading Research and Policy at Parkinson's UK. Robert has played a leading role in partnerships that secured legislative changes to permit stem cell research and cuttingedge genetic treatments in the UK
- Duncan Boak is the Founder of Fifth Sense and the Chair of the Board of Trustees. In Duncan's own words: "In 2005, as the result of a severe head injury, I lost my sense of smell. Before then, like most people, I took this sense for granted and had little understanding of the contribution it made to my quality of life. Told that I would just have to live with it by my doctor, I spent over six years thinking I was one of a handful of people on the planet affected by this hidden condition, but without fully understanding or engaging with my loss. My goal was to create the organisation that I wish had existed to support me with my loss; a charity to help and inform people affected by smell and taste disorders, transform society's understanding of the importance of these senses and drive research into better understanding and treating these conditions. I'm incredibly proud of the organisation we've created, our values and ethics and our fantastic team of staff, trustees, volunteers and advisors."

Appendix Three

Proposed Staffing Structure for Fifth Sense

