Citizens Academy

I Smell - Engaging Users in Smell Self Care At Home

Public Partner Information

UEA
University of East Anglia

The Citizens Academy

The Citizen's Academy (CA) is based within the Faculty of Medicine and Health. It represents a coordinated approach to involving members of the public, patients, and experts with relevant experience across all aspects of teaching and research. For further information about the Citizen's Academy, or to find out how we can help you, contact us at:

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Project Details

Project Title:

I Smell - Engaging Users in Smell Self Care At Home

Chief Investigator:

Professor Mariana Obrist

Project PPI Lead:

Professor Carl Philpott

Collaborators:

Dr Ava Fatah (Bartlett School of Architecture), UCL, Fifth Sense, Future Care Capital

Project Sponsor Organisation:

UCL

Funding Programme:

EPSRC

Award Amount:

£500,000

Award Start Date:

1/10/2022

Award End Date:

30/9/24

Project Website:

TBC

Plain English Summary of the Research:

Smell disorders have long been neglected, despite known links to Parkinson's, dementia and to shorter life expectancy. Recent public and patient engagement work by the charity Fifth Sense (FS) has shown a failure to provide a good service for such patients in the UK. It also showed the need for better treatment and support. This lack of support has been made worse in the COVID-pandemic, leaving patients and doctors struggling to advise those affected by smell disorders. This adds to the mental health problems that are linked to the loss of smell. To date, based on UK infection rates, nearly 500,000 people have lasting symptoms of smell loss or change (>4 weeks). These may be linked to other Long-COVID symptoms such as fatigue, memory problems and brain fog.

Smell training, a type of smell care, now has several studies showing it can help recover smell function. This is very true in older people, where people suffer a natural decline of the sense of smell. However, current smell training methods are limited to pens soaked in smells or jars of essential oils. A digital solution can overcome these drawbacks and enable digital smell training. This may be delivered in multiple settings including medical, care homes and private homes. The latter sits at the heart of this project's ambition, namely, to enable smell self-care (I-smell) at home.

A key question this project will try to answer is how and why people will take on and accept I-smell, and keep using it in regular, daily exercises? We all know that it is hard work to set up a routine and keeping it, is even harder. Whilst more people are aware of the importance of smell care in the wider public due to the pandemic, it is easily forgotten and lost when the sense of smell works or seems to work 'well' again.

We will study how I-smell is taken into daily routines and any barriers to that. This will be measured by looking at the impact on people's quality of life and wellbeing. We will gain first-hand early-stage user feedback from chosen households that will take part in a 6-month feasibility study using a novel digital technology in their homes. We aim to establish a clear understanding of peoples' underlying reasons, opinions and motivations to engage with I-smell over time.

This feasibility study will inform the design of future health and care technology solutions, as well as informing the design of future clinical and population trials. It will also allow us to explore designs for tomorrow's home that go beyond the current focus on control of environmental conditions such as energy, lighting, temperature and humidity. We will consider how this type of technology will work with existing smart home devices such as Google Home or Alexa. Our long-term vision is to add self-monitoring records for our sense of smell (akin to hearing and sight tests) into electronic health records (EHR). This would provide a great opportunity to make treatments personal for individuals and allow timely actions by GPs. For example, data could be analysed by artificial intelligence that could lead to earlier diagnosis of diseases like Parkinson's by a decade. Introducing digital solutions for smell self-care can help maintain and extend independent living at home and improve the quality of life.

Insert plain English summary of the research project. Please refer to NIHR's guidance on writing plain English summaries.

Expected Output of the Research:

1. **Objective 1: Co-design and deploy the I-smell technology probe [WP1]:** To adapt an existing early stage 6-channel scent-delivery device and self-monitoring App for I-smell, to enable a first-ever longitudinal home deployment, to iteratively co-design the App based on user feedback.

2. **Objective 2: Evaluate users' acceptability and I-smell engagement [WP2]:** To collect user feedback in a feasibility study in real-world home settings, to apply a mixed method approach to involve users in pre-, during, and post-deployment feedback and the assessment of the impact of I-smell on QoL.

3. **Objective 3: Map out research and impact pathways for I-smell [WP3]:** To engage in a collaborative sense-making process to map out future research directions for larger scale clinical trials, in the-wild home-design explorations, and advances in digital health & care technology development.

We aim to disseminate our contribution widely across the UK and beyond, in academic conferences and journals across all the different disciplines represented in the project (HCI, medical science, built environment), through targeted panel/workshop discussions, and public events aligned with project partners' PPI activities (e.g. Fifth Sense regular webinars and Future Care Capital panel events). Moreover, we will tie our efforts in with Fifth Sense, who are in the process of establishing a London-based community Hub in 2022 focused on healthy ageing, extending their Hubs in North East & North West of England (Newcastle, Manchester). This offers mutual benefits for community building and engagement and connects Fifth Sense with the efforts of Future Care Capital on social care/healthy ageing, enabling collaborations into care homes. Through our regular meet-ups and local events, we will promote a culture of smell self-care as part of a proactive and preventive health & wellbeing society for improved QoL and longer independence.

Role of Public Partner(s) for this Project:

As part of work package 3 (WP3) the PPI panel will meet in person at the beginning and the end, aligned with the participatory workshops and the final event, and throughout on a bi-monthly basis (virtual/remote or whenever possible in person). This will allow the project team to share updates, ask questions and advise on procedures, results, and outcome, and identify new activities and stakeholders to engage with. Those meetings will enable reflection to act in a timely throughout the project and gather lessons for future research pathways (input WP3). Panels members will be expected to attend in person/online (Teams/Zoom) bi-monthly meetings (hosted at UEA for those attending in person). The meetings will last approximately 1-2 hours and this will include time before and after each meeting for you to raise any queries you might have. We will email you documents to read in advance of the meeting which should take no longer than 30 minutes to read. We will aim to have the first meeting fully face-to-face at UEA but with subsequent meetings being hybrid according to panel availability.

At the meetings, we would like to encourage you to raise any questions you might have and contribute to discussion within the group representing the patient/public perspective.

Workshop Activity:

To support the horizon mapping aim of WP3, we will organise two rounds of speculative design (SD) workshops in the second year of the project. SD is a catalyst for collectively reimagining possible, probable, plausible, and preferable futures. While scientific and technological advances serve as key 'signals' to facilitate the speculation about the future, it is the 'human lived experience' that remains at the heart of the investigation. We will invite the PPI panel to join project partners, stakeholders from backgrounds in healthcare innovation, healthcare, built environments, and reach out to local community & end user representatives, policy/decision makers in social care and digital health experts, drawing on the project team's extensive network. We will also reach out to artists/practitioners (e.g. designers, performers from UCL enterprise residencies) to challenge existing thinking and collectively explore possible and desirable futures that many of us can't yet imagine.

Future planning:

The PPI Panel will also contribute to map out relevant future research directions for the next-stage, large scale ambitions to transform future care and health. The pathways will be inherently cross-disciplinary reflecting the project team's expertise:
(i) opportunities for novel technology development and innovation for digital health and wellbeing applications
(ii) informing hypothesis testing in consequent clinical research trials based on the insights gained from this first-ever field deployment around smell care and self-smell care
(iii) guide design exploration for tomorrows' homes and ICT integration

Renumeration:

Event remuneration will be as follows:

• Participatory design: 3 workshops for 20 people at £45 per person
• Two Speculative Design Workshops x 20 people at £45 per person
• Free refreshments for 6 Meet-ups
• PPI Panel and final project event; 100 people at £45 per person

As a reimbursement to acknowledge PPI partners' valuable input, we would like to provide public partners with payments at the rate set out above which will include allowance for any travel costs. The project PPI lead will discuss payment options with you and help with the administration process. If you are to be paid, a Right to Work check will need to be carried out and this will involve providing There may be implications for being paid for involvement whether you are employed, unemployed, receiving state benefits or retired. The payment you receive will be treated as earnings. It is your choice whether or not to accept payment for involvement and should you do so, it is your responsibility to declare earnings to HMRC or Jobcentre should this be necessary. For more information about how payment for involvement might affect you, please see Payment guidance for members of the public considering involvement in research | NIHR.

If you are worried about how payments might affect your benefits and this is a project funded by NIHR, you can contact the NIHR Benefits Advice Service for public involvement in research: https://sphr.nihr.ac.uk/news-and-events/nihr-benefits-advice-service-for-public-involvement-in-research/

Please refer to the CA and RIN/R&D for advice on how to offer and administer payment to public partners. Discuss payment options with public partners. If paying in vouchers, it is important to ask public partners their preferences. Example e-gift cards include the Gift Card Centre with over 180 cards to choose from, love2shop which has a multi retailer card which can be spent at 90 retailers and Amazon. Please do not purchase the vouchers yourself. For audit purposes and to prevent fraud, it is important that the finance office purchase the vouchers. If the public partner(s) are to be involved in the project in an ongoing capacity, being set up on the payroll is the preferred option. For payroll, a right to work check will need to be carried out, for example, through provision and copy of an original document such as a passport. For further information, please contact RIN/your host R&D department.

Support

We would like to support you when undertaking your role. Please feel free to contact the named PPI lead with any questions you may have in the first instance. You may also contact the Citizen's Academy directly.

There are several free online training events, online courses and printed resources aimed at members of the public explaining the research environment and public involvement. We have listed a few of these below.

Online training courses:

- NIHR Cambridge Biomedical Research Centre PPI events and training, including 'Understanding clinical research' and 'Joining a committee on health research as a PPI member': https://cambridgebrc.nihr.ac.uk/public/online-ppi-events-training/

- Free online interactive course for public reviewers:
https://www.invo.org.uk/resource-centre/learning-and-development/public-reviewing-with-the-national-institute-for-health-research-nihr/

- Free Massive online open course (MOOCs) 'Improving healthcare through clinical research' and "What is Health Research?':
https://sites.google.com/nihr.ac.uk/massive-open-online-courses/about?authuser=0

Online training resources:

- Learning for Involvement. Search training events and resources:
http://learningforinvolvement.org.uk/

- INVOLVE learning and development resource centre:
https://www.invo.org.uk/resource-centre/learning-and-development/

- Starting Out guide for public contributors:
https://www.invo.org.uk/wp-content/uploads/2019/10/Starting-Out-Revised-FINAL.pdf

- Public Information Pack (PIP). Four booklets:
https://www.invo.org.uk/wp-content/uploads/2019/04/PIP12019.pdf