

SENSE-COG NEWS | ISSUE 1 | APRIL 2018



Welcome to SENSE-Cog April 2018 Newsletter!

Welcome to the first issue of SENSE-Cog News! We hope these bi-annual newsletters will inform you about the SENSE-Cog programme and update you on our progress to date and our plans for the future. This edition will focus on our team in Manchester, and future editions will focus in on our different partner sites in Europe.

Contents

- [SENSE-Cog at a glance](#)
- [What have we achieved?](#)
- [Plans ahead](#)
- [SENSE-Cog at Work](#)
- [Meet the team @ Manchester](#)
- [Connect with us!](#)

SENSE-Cog at a glance

SENSE-Cog *Promoting health for eyes, ears and mind* is a five year programme, led by The University of Manchester, with collaborators in France, Germany, Cyprus, Greece, Norway and USA, it aims to investigate the combined impact of dementia, age-related hearing and/or vision problems and to develop new tools that could improve quality of life and make the best use of health and social care budgets across Europe. The project started in January 2016 and will run until December 2020, and is supported financially by the European Union's Framework Programme for Research and Innovation, Horizon 2020. SENSE-Cog consists of 7 work packages (WP) interconnected as shown below (click on the picture to enlarge):



Details of the SENSE-Cog consortium and partners can be found on our website ➡ www.sense-cog.eu. Project management support for SENSE-Cog is provided by ➡ ARTTIC.

What have we achieved?

WP 1: Exploration

We now know more about the links between anxiety and depression and hearing and vision problems. We have found that: (1) having both hearing and vision problems may pose a significantly increased risk for depression in older people; (2) that mild and severe hearing loss is associated with new onset depression; (3) that anxiety is uniquely related to hearing loss and over a several year period mild anxiety symptoms may emerge; and (4) that risk of suicide is greater in older people with hearing and/or vision loss or both.

WP 2: Assessment

We have identified the need to improve cognitive assessments for people with hearing and vision problems and have begun to develop an on-line screening tool for people to self-manage their sensory and cognitive health. The tool helps people determine whether they have a clinically significant hearing, vision or memory problem. Understanding this will help to increase the likelihood of early identification and treatment of these problems. The tool will be inexpensive and widely available via smartphone and computer platforms, usable by non-experts, and applicable with hard-to-reach populations.

WP 3: Intervention

We have now determined: (1) our beliefs and assumptions about how the intervention might work and lead to change for an individual; (2) the method to assess participants' level of hearing and vision problems and range of functional needs in the home; (3) how the intervention will be tailored to the specific needs of the participant; (4) what the individual elements of the intervention will be; and (5) how the intervention will be implemented (e.g. duration, frequency and delivery of each component); and (7) how the intervention will work in the context of different EU settings.

WP 4: Valuation

Our economic analysis has already contributed important new findings by revealing that, for some people, memory, vision and hearing problems are significantly associated with higher use of health care services (e.g. more hospitalisations and GP visits), even when the other health conditions experienced by people are taken into account. This strengthens the case for improved recognition and support of these frequently co-occurring conditions in older people across Europe. This work has resulted in an important approach to doing this analysis. The findings now enable us to determine the best available resource use and quality of life scales for dementia-related trial health economic analyses.

WP 5: Involvement

We have established a network of Research User Groups or RUGs, each comprised of 7-10 people living with cognitive ill-health and/or hearing/vision impairment and their friends and family. The groups have received some training on the principles of research to empower them to input meaningfully into the SENSE-Cog research programme. The groups meet regularly to support and input into SENSE-Cog research. So far they have inputted into the appropriateness of the study materials, which research questions to focus on, the ways in which research participants should be recruited to the study, the acceptability and tolerability of the chosen outcome measures, the clinical meaningfulness of results, and how to tell people about the results of the research.

Plans ahead

In future months:

The WP2 team are continuing with the development of the on-line screening tool and validation of adapted assessments.

The WP3 team are ready to start the full-scale, multi-centred randomised controlled trial (RCT) of the newly developed 'sensory support intervention'. In order to get to this point they have:

- Developed the role of the 'sensory support therapist' (a new type of professional), training materials and treatment manual for this role. A 'prototype' therapist and senior therapist joined the team to take this work forward in preparation for the RCT.

The WP4 team are looking at whether and how cost effective the 'sensory support intervention' is. This is crucial to the eventual implementation of the intervention in clinical services across the EU, if it is found to be effective.

The WP5 team are involved in formally evaluating their methods of patient and carer involvement to ensure that SENSE-Cog will provide a gold standard model for public involvement in health research in Europe.

SENSE-Cog at Work

Hearing impairment on people living with dementia

In January 2018 Manchester Institute for Collaborative Research on Ageing at the University of Manchester, ran a seminar for their network to hear about some of the SENSE-Cog findings [Impact, identification and management of hearing loss in people with dementia](#) led by Dr. Piers Dawes. At the seminar SENSE-Cog findings were discussed along with other on-going projects looking at the impact of hearing impairment on people living with dementia, including how doctors should assess people for dementia when people have a hearing problem and how to reduce the impact of hearing impairment for people living with dementia. This seminar was well attended and received positive feedback as well as some lively debate from the audience.

Quality of Life in the Elderly: The Role of Memory, Hearing and Vision - Public event in Nicosia

Our team in Nicosia (University of Cyprus and the European University of Cyprus) held a public event to inform the public about the free hearing, vision and memory screenings for adults over 60, and delivered lectures on memory, vision and hearing. The lectures covered the separation of normal aging from dementia and strategies to improve memory, the role of hearing and vision in

memory, the relationship between dementia and depression in patients and carers, and information on supportive services and benefits of the State for Disabled People.



Hearing loss in older adults is associated with increased anxiety symptoms!

Suzie Cosh worked as a post-doctoral fellow at University of Bordeaux, and has recently published a study entitled "Bidirectional relationships between vision and hearing loss with anxiety: prospective findings from the Three-City Study", for more information visit [SENSE-Cog Publications](#). The key findings from the study were:

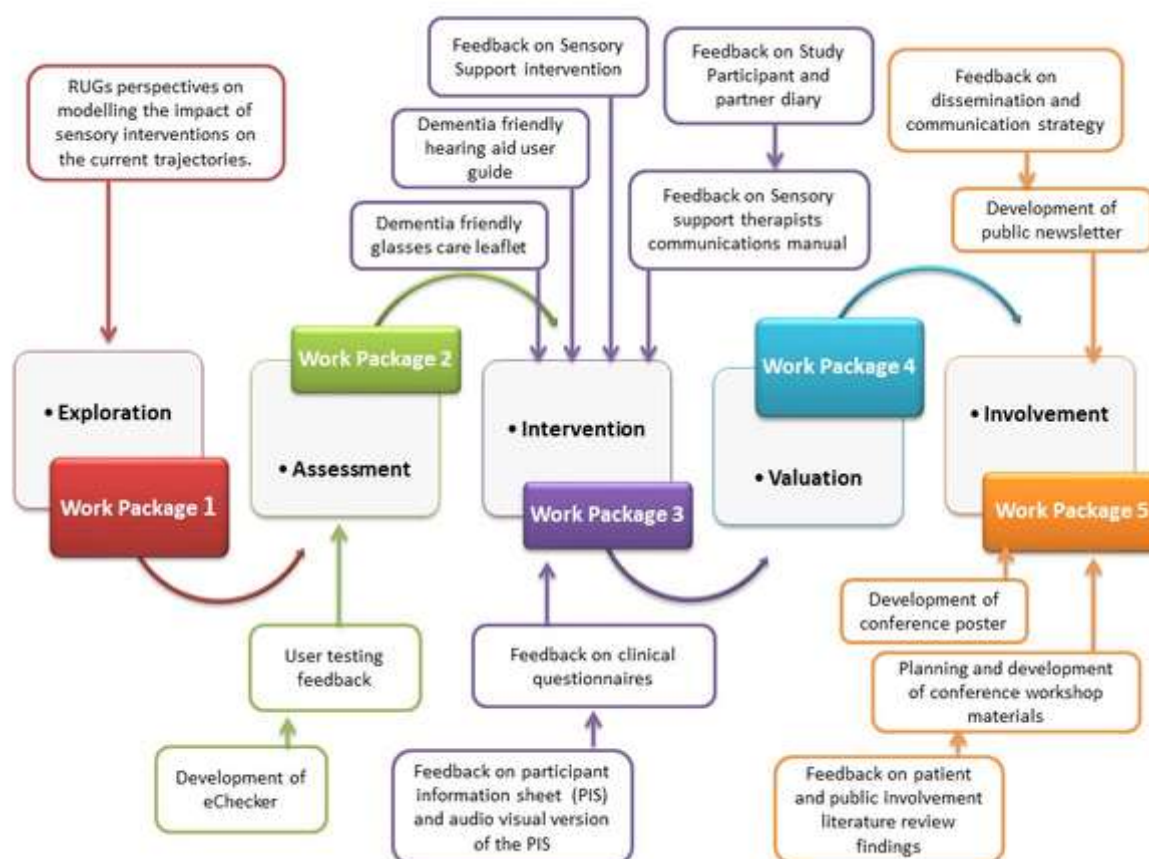
- Hearing loss in older adults is associated with increased anxiety symptoms.
- There was no evidence of a longitudinal association between vision loss and anxiety.
- A history of Generalized Anxiety Disorder increases risk of self-reporting a new onset of hearing loss.
- This study provides the first longitudinal examination of relationships between sensory loss and anxiety.



Suzie has moved on from SENSE-Cog and is now working in sunny Australia as a lecturer in Clinical Psychology, at the University of New England!

Our Research User Groups – Creating Patient and Public Voice!

We have a network of Research User Groups (RUGs) established in Manchester, Nice, Nicosia and Athens. Research User Groups consist of older Europeans with 'lived experiences' of anxiety and depression, dementia, and/or sensory problems and their carers. RUGs are receiving on-going training to provide input to each work package within the SENSE-Cog project and to date have provided specific input on various aspects of the project illustrated in the diagram below (click on the picture to enlarge)

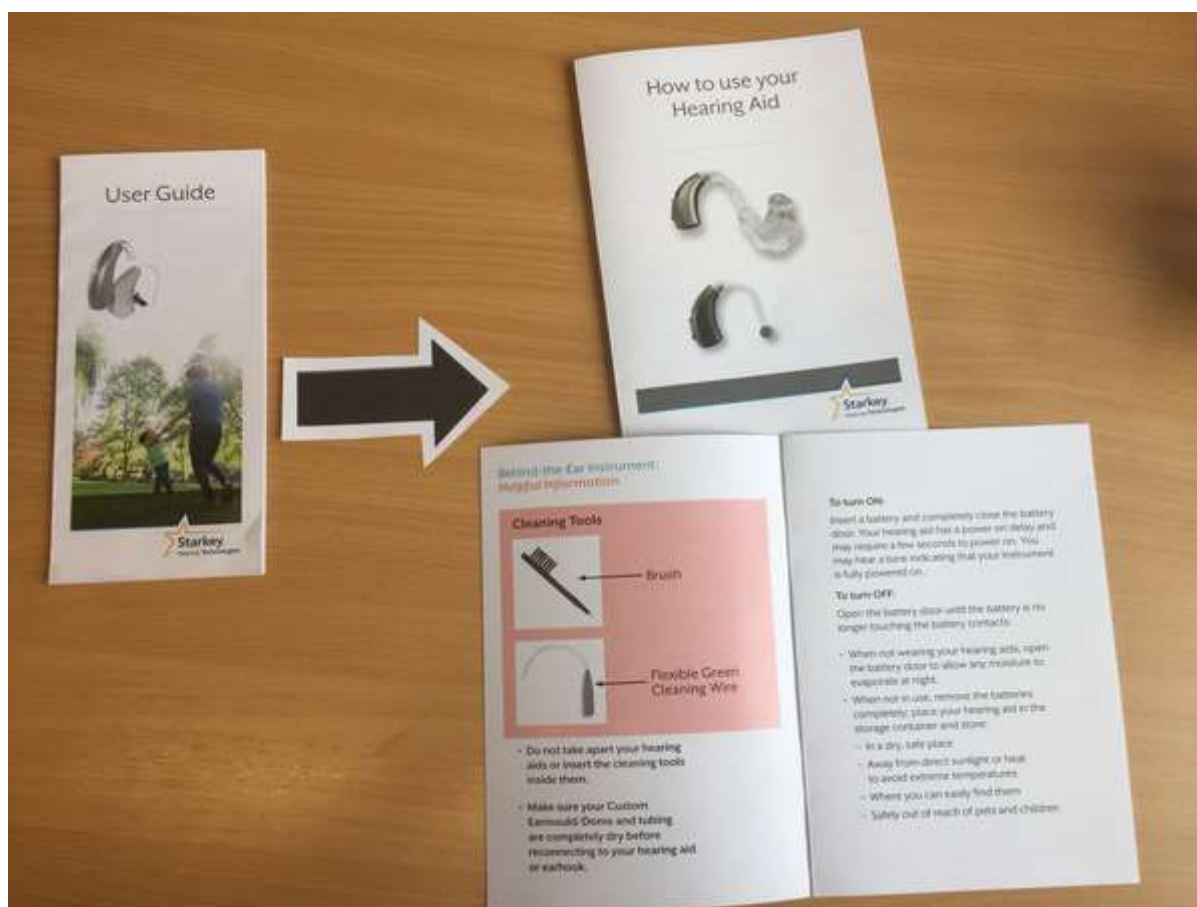


Manchester RUG at work:

RUGs members discussing with Starkey colleagues (Sue Falkingham and Vicky Lowery) how to make the hearing aid user guide dementia friendly. This guide will be used during the Sensory support intervention trial. User testing the on-line eChecker for hearing, vision and cognition components.



Starkey leaflets changes: Dementia friendly guidance leaflets produced! The guide How to use your Hearing Aid can be found in the section Guides on bottom page www.sense-cog.eu/publications/.



RUGs using role play to review the Communication Guidance from the Sensory Support Therapist's (SST) Manual to be used for Randomised Controlled Trial (RCT) (upper picture). RUGs taking part in Research Awareness Training, thinking about how they could use the research process in planning their next summer holiday (lower picture)!



My experience as a carer...



Hello, my name is Doreen, I've been with Manchester Research User Group (RUG) for nearly 2 years now. I've been looking after my partner for about 20 years, he's had Parkinson's for 27 years, and in the last 3 years he was diagnosed with dementia, but I think he had dementia for much longer than that, I kept saying at the hospital that there's something wrong with his memory but nobody picked it up. As time progressed, it's been difficult to really understand what's been happening to him. There have been times, when I've talked and talked to him, but sometimes he would seem to be in a world of his own, not listening to what I was saying. It made me wonder if he was listening to me, or just blocking me out and not responding. This used to frustrate me and I used get to get angry, thinking I'm being ignored. But I didn't realise that it

was part of his condition, that he wasn't hearing what I was saying or that his brain wasn't responding to what I was saying, or not understanding things, but I didn't know which one was causing which, was it the hearing or the dementia or was it both causing him to be like this. This caused me distress and a lot of frustration.

I got to know about SENSE-Cog at a carers meeting or Age UK meeting, I can't remember exactly where, but I remember someone mentioning if I would be interested in getting involved with the SENSE-Cog RUG. So, I signed up for this, thinking it could help me to understand what was happening to my partner and also any input that I could have might help other people further down the line that may be experiencing some of the problems I've been having. I wanted to give something back and if I could learn something to help my partner and make it easier for other people too, by helping researchers to find solutions to help people like myself and my partner. I was interested to get as much insight into dementia and the understanding of why it was happening and how it was functioning in cognitive terms.

As I mentioned earlier, at the beginning I didn't understand the connections between hearing, vision and cognition, that they affected each other. So through being involved with the RUG, it has helped me to understand things better and make sense of why my partner was the way he was. I really wanted to give something back into the world, as I've received a lot of help from others. I enjoy being part of the group, meeting with other people in similar situations and it makes you realise that you are not on your own. The people that run the group have been understanding and it's hard to explain, I felt that the people running the group really care and are understanding, made me feel like we belong, always there to listen, never judged and everyone's made you feel at ease. It's been a good experience, I've learnt new things, which has helped me to make sense of things and I've also helped the researchers to do their work by sharing my experience. The different speakers and researchers that have come to the meeting and telling us different things, is something that I would never been involved with if I hadn't been involved with the RUG.

News from Athens!

The clinical site at the University of Athens has received ethical approval, earlier than expected, for all work packages involved, with only some documents left to be translated in Greek. Athens' Research Team is formed and awaiting to implement effectively all next tasks. Meanwhile, the SENSE-Cog project is being communicated and promoted in conferences by the Principal Investigator in Athens, Associate Professor A. Politis.

Recently a RUG was also formed in Athens. The RUG has 9 enthusiastic and motivated members, both care-receivers and companions. They have completed four sessions of the Research Awareness Training and our group members are really interested in the work of the RUGs in other countries and generally in the progress of the work that has already been done in the SENSE-Cog Project.



Meet the team @Manchester

Chief Investigator - Iracema Leroi

Iracema Leroi is a Professor of Psychiatry in Aging and Dementia at the University of Manchester and an honorary consultant psychiatrist at Greater Manchester NHS Foundation Trust. Professor Leroi is the lead Investigator for SENSE-Cog.

She leads the clinical dementia research group at the university and is Director of the Greater Manchester Dementia Research Centre, which focuses on clinical dementia research in the NHS. She trained in Canada and at Johns Hopkins University School of Medicine in the USA. She moved to the UK in 2002 to continue her work in the mental health and cognitive aspects of Parkinson's disease and other dementias. Her current research focuses on three areas:

- (1) developing and evaluating complex non-pharmacological interventions for dementias;
- (2) applying and evaluating new technologies for the diagnosis and care of conditions leading to dementia; and
- (3) leading a clinical trials' programme for potential new drug therapies for Alzheimer disease.

Co-investigator - Piers Dawes



Piers background is in experimental psychology, with an interest in the cognitive aspects of hearing, and research interests include hearing loss, auditory processing and developmental psychology from childhood to old age, auditory plasticity, hearing genetics and developmental disorders. Piers was a 2013-2014 US-UK Fulbright scholar, and was awarded the British Society of Audiology's Thomas Simm Littler Prize in 2014 for his work on the epidemiology of hearing loss and acclimatization to hearing aids.



All sites RCT training with the team at Manchester University.

Public Programmes Team (Manchester based) - key collaborating partners and co-leads work Package 5

The Public Programmes Team is a specialist unit which advises on and delivers patient and public involvement and engagement across Greater Manchester, nationally and internationally. It is hosted by Manchester University Hospitals' NHS Foundation Trust in partnership with the [University of Manchester](#). It's strategic focus areas are:

- **Prioritising diversity and inclusion** within our contributors, audiences and approaches
- Experimenting with arts-led approaches; **innovating across engagement and involvement**
- Delivering **gold standard evaluation and research** informing a continuous cycle of innovation and improvement in our practice
- **Building capacity for engagement and involvement** within researchers and public contributors.

Suzanne Parsons, the Patient and Public Involvement Manager with the Public Programmes Team, is the co-lead for work package 5. For work package 5, she provides strategic advice on project design and delivery, avenues for dissemination, research support and learning.

The Public Programmes Team have worked to provide training and development for our patients and public voice champions in Manchester, Nice, Nicosia, and Athens and support to effectively involve the Research User Groups in SENSE-Cog. This has led to the introduction of a new way of working with patients and public in the research context. The patient and public voice champions directly support, manages and trains our Research User Group in each study sites. For more information visit: [Public-programmes](#)



MICRA

[MICRA \(Manchester Institute for Collaborative Research on Ageing\)](#) is pleased to support SENSE-Cog. At MICRA we believe that developing interdisciplinary research is a key task for advancing work in the field of ageing. At MICRA international experts address fundamental questions about ageing and society through collaborative research across the biological, medical and physical sciences, the social sciences and the arts and humanities. We engage critically with stakeholders and policy makers at all levels to deliver research with demonstrable impact. MICRA hosts a programme of seminars and events each academic year to support ageing research. Our seminars are free, open to all and attract audiences of up to 100 including researchers, care providers, older people, local government, NHS and the private sector.

Upcoming events in SENSE-Cog

SENSE-Cog Qualitative Workshop GTM on 3-4 May 2018 in Freiburg, Germany at the premises of Katholische Hochschule Freiburg GGmbH (CUF). The program can be seen [here](#).

Next SENSE-Cog annual project meeting and public event will take place at the premises of University of Cyprus in Nicosia, on 24-26 October 2018.

Connect with us!

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