SENSE-COG NEWS | ISSUE 3 | MAY 2019



Welcome to SENSE-Cog May 2019 newsletter!

Welcome to the third edition of SENSE-Cog News! We hope these bi-annual newsletters will inform you about SENSE-Cog programme and provide you with our progress to date, tell you about our plans for the future, upcoming events and what individual members of the consortium have been up to. This edition will focus on our team in Nice. For the French and Greek version of this newsletter please click on the corresponding flag below.



Contents

- <u>SENSE-Cog at work</u>
- Meet the team @ Nice
- <u>Publications of interest</u>
- <u>Connect with us!</u>

SENSE-Cog at work

A randomised controlled trial of sensory support to improve mental well-being in people with dementia and their caregivers - Updates

The trial involves a sensory support therapist's assessment of the person with dementia including their level of hearing and vision impairment and their range of functional needs in a home-based setting. The intervention (support offered) is then tailored to the specific needs of the participant and the individual components of intervention identified for the participant. Five sites are participating in the trial: Manchester (UK) have recruited 29 participants, Nice (France) 7 participants, Nicosia (Cyprus) 4 participants and Athens (Greece) 19 participants. Dublin (Ireland) is due to start recruiting soon.

Updates from Athens

The clinical site of the University of Athens has already started recruiting dyads (person with dementia and their carer or significant other) and running the validation and the randomised control trial and there is a lot of interest from research participants. The Research Users Group

have provided valuable feedback regarding questionnaires that evaluate the dependence of dementia patients.

Due to the existing interest in this area in the Greek community, there has been a number of conference presentations and interviews with the Greek media regarding the concurrence of cognitive, hearing and vision impairments. Interview and article links are below:

- Go to interview (Greek)
- Go to article (Greek)

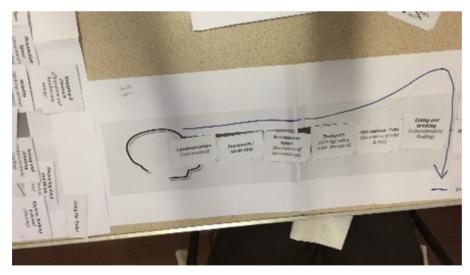
Photo collage: Athens Research User Group Meeting



Research User Groups input into the economic model for the SENSE-Cog intervention

Work Package 4 (the valuation package) team conducted the two health economics focused Research User Group (RUG) meetings. The meeting was surrounding the economic model for the SENSE-Cog intervention. The RUGs were asked to discuss their personal experiences of dementia progression as defined by "dependence". The aim of the session was to discuss dementia progression with people who have lived experience on the topic, in order for the team to represent this progression in a meaningful way within the economic model. The session went well, with the RUG members working individually on the timelines of activities of daily living (ADL). The timeline was developed to represent when a person with dementia may need help with particular ADLs within their dementia journey. Following this exercise, there was an open and lively discussion regarding "dependence milestones". The group highlighted activities such as driving, communication and the preparation of food and drink as being particular stand-out ADLs.

Photo collage: Manchester RUG member's description of the dementia journey



SENSE-Cog NEWS | Issue 3 | May 2019



Greater Manchester Symposium brings together professionals in hearing, vision and dementia 5th April 2019

SENSE-Cog teamed up with MICRA (Manchester Institute for Collaborative Research on Ageing) and Greater Manchester Strategic Clinical Network to deliver a symposium to bring together professionals in hearing, vision and dementia. The aim of the symposium was to raise awareness of the prevalence, impact and management of age-related hearing & vision impairments in people with dementia and work towards developing a set of interdisciplinary clinical guidelines to support people with dementia with hearing and/or vision impairment.

Plenary speakers included Michael Bowen, Director of Research at The College of Optometrists speaking on the prevalence of visual impairment in dementia and British Academy of Audiology President Sue Falkingham spoke to delegates about Audiology and its impact on people living with dementia.

Delegates included clinical and non-clinical professionals in vision, hearing health and dementia care, commissioners, managers of older people's services in NHS, care homes and community care, charities and interest groups in vision, hearing health and dementia care. The delegates worked on recommendations for guidelines for optimising hearing and vision care for those with dementia.



Photo collage: Professionals in hearing, vision and dementia worked on recommendations for guidelines for optimising hearing and vision care for those with dementia.

SENSE-Cog Asia Feasibility study

SENSE-Cog NEWS | Issue 3 | May 2019

To address the global health priority of neurocognitive aging, including the rising prevalence of cooccurring age-related cognitive and sensory impairments in older people particularly in low and middle income countries (LMICs), we are aiming to undertake an open-label feasibility study of a culturally adapted intervention of hearing health in people with dementia across seven sites in three South Asian countries. This study is a bolt-on investigation to Work Package 3 in the European SENSE-Cog programme. The potential to extend this approach to LMICs is great and will enable the use and adaptation of existing resources and infrastructures to support research and care pathways for dementia and sensory health in South Asia. The study has already received favourable ethics approval from the University of Manchester and is currently in the process of training the staff and setting up the study in seven sites across India, Pakistan and Bangladesh.

Photo Collage: SENSE-Cog Asia launch in Dhaka 9th March 2019. 97 delegates in attendance to support the programme in partnership with Renaissance Hospital & Research Institute Ltd, Hearing Care Centre Ltd, Bangladesh and Sir William Beveridge Foundation.



Care Home study

This study aims to understand the knowledge, attitudes and practices of residential care facility staff and family members of residents, regarding the hearing and vision health of people with dementia living in residential aged care facility settings. The study has the ultimate aim of implementing change and improving quality of life and other dementia-related outcomes for older people who are care home residents. The survey is being completed by care facility managers, nurses and allied health professionals, paid caregivers and family and friends of people living with dementia in residential aged care facilities across the UK and several international sites. The study will soon be coming to a close, having reached its recruitment target.

Meet the team @ Nice



Philippe Robert is Professor of Psychiatry at the Université Côte d'Azur and Director of the Cognition, Behavior & Technology (CoBTeK-lab) team. His areas of expertise include behavioural and psychological symptoms and especially motivation disorders, evaluation and treatment of

apathy, and the use of new technologies for diagnosis and stimulation in neuropsychiatric pathologies.



Renaud David is a physician at the Nice University memory Center. His fields of expertise are the study of cognitive and psychological symptoms in ageing and neurodegenerative disorders, the movement analysis and the use of information and communication technologies for the early diagnosis and the non-pharmacological management of cognitive and behavioural disorders in older adults.



Valeria Manera is a postdoctoral fellow at the CoBTeK unit of the University of Nice-Sophia Antipolis. She has a Master degree in Clinical Psychology and a PhD in Cognitive Science. Her domains of expertise include apathy, emotion recognition and regulation, and dementia prevention. She works with the Nice Research User Group and SENSE-Cog research team.



Alexandra König's background is in Neuropsychology, Geriatrics, Neurology and Psychiatry. She is involved in the qualitative analysis of the interviews with the participants of the Work Package 3 intervention.



Marion Ferrandez is a researcher for work package 2 and 3, she has a background in psychology and neuropsychology of cognitive disturbances. She is working in Nice Memory Center - University hospital on research programs about new technologies and cognition.



Magali Payne is the Sensory Support Therapist on work package 3. She is a speech therapist and a teacher in the speech and language pathology department of Nice University. She is a PhD student, working on Alzheimer dementia and olfactive disease.



Justine Lemaire is an engineer in biotechnology, she is the study coordinator supporting investigators in all clinical trials ongoing at the Nice memory center including SENSE-Cog: prescreening, data entry, quality control.

Publications of interest

- A discussion paper on hearing interventions as a way of preventing dementia: <u>https://link.springer.com/article/10.1007/s00106-019-0617-7</u>
- A protocol paper to evaluate the impact of involvement of older people with dementia and age-related hearing and/or vision impairment in a multi-site European research study: https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-018-0128-9
- Protocol for the development of versions of the Montreal Cognitive Assessment (MoCA) for people with hearing or vision impairment: <u>https://bmjopen.bmj.com/content/9/3/e026246</u>
- Associations between self-reported sensory impairment and risk of cognitive decline and impairment in the Health and Retirement Study (HRS) cohort: <u>http://dx.doi.org/10.1093/geronb/gbz043</u>

Connect with us!

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