SENSE-COG NEWS | ISSUE 4 | NOVEMBER 2019





# Welcome to SENSE-Cog November 2019 Newsletter!

Welcome to the fourth edition of SENSE-Cog News! We hope these bi-annual newsletters will 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 focuses on our team in Athens. For the French and Greek version of this newsletter please click on the corresponding flag below.





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## **SENSE-Cog at work**

# Update on trial of sensory support to improve mental well-being in people with dementia and their caregivers

The trial looks at hearing and vision support provided by a sensory therapist to people with dementia in their homes. The trial will find out if sensory support gives improved mental well-being for people with dementia. The hearing and vision support is tailored to the specific needs of each person.

Seven sites are now participating in the trial. To date, UK sites (Manchester, Lancashire and Warrington) have recruited 46 dyads (person with dementia and care partner), Athens (Greece) 31 dyads, Nicosia (Cyprus) 23 dyads, Nice (France) 18 dyads, and Dublin (Ireland) 10 dyads. People involved in the trial report that the hearing and vision support is useful, and that it is interesting to be involved in the trial.

### Updates from University of Athens, Eginition Hospital

The University of Athens is still recruiting people for the studies to develop better assessments and the trial. There has been lots of interest from the community, but more people are urgently needed! Please contact Maria Passa or Kontogianni Evangelia: <a href="mailto:sensecoghellas@gmail.com">sensecoghellas@gmail.com</a> if you might know of anyone who would like to take part.

Members of the Athens team are going to conferences to talk about the great work being done in SENSE-Cog. The Athens team recently presented about SENSE-Cog and participated in a workshop entitled "European Join Actions on Dementia: The Hellenic implemented projects" at Eginition Hospital in Athens.



Photo caption: Evangelia Kontogianni and Antonios Politis talking about the SENSE-Cog programme at "European Join Actions on Dementia: The Hellenic implemented projects" at Eginition Hospital in Athens.

### Taking SENSE-Cog to Brazil

Our lead sensory support therapist Emma Hooper was one of seven researchers from the UK chosen to attend the first UK-Brazil dementia research workshop in Belo Horizonte, Brazil, from 25 - 27th July 2019.

Emma joined twenty Brazilian researchers to explore challenges in (mis)perceptions, (mis)diagnosis and care management of cognitive impairment and dementia. The workshop was facilitated by researchers from the Federal University of Minas Gerais and the University of East Anglia. The workshop was a great opportunity to present the SENSE-Cog work that Emma is involved in and to build international networks with other dementia researchers.





Photo caption: Emma Hooper with Brazilian researchers exploring challenges in (mis)perceptions, (mis)diagnosis and care management of cognitive impairment and dementia at the UK-Brazil dementia research workshop in Belo Horizonte, Brazil, July 2019.

### How to measure support needs in dementia research?

At the Primary Care Mental Health Research Conference (PCMH) 2019, Hannah Hussain presented her work on the importance of looking at the cost of support needs in activities of daily living activities for people with dementia participating in research studies. Activities of daily living ranges from basic activities such as clothing and bathing to more instrumental activities, such as shopping and food preparation. Hannah is a health economist at The University of Manchester, working on SENSE-Cog.

Hannah's presentation outlined the SENSE-Cog project overall and gave some early results from a review her team did looking at how to account for changes in the cost of people's support needs in research studies. Hannah's talk was given to mental health researchers, doctors and mental health care staff. The talk was at The University of Manchester on 23rd May 2019. The theme of this year's event was 'Forward Thinking in Primary Care Mental Health Research'.

Hannah also presented this work at the International Society for Pharmacoeconomics and Outcomes conference in Copenhagen, Denmark from 2nd - 6th November 2019. This international conference was attended by policymakers, regulators, researchers, academics, payers and patient groups from all over the world.

#### Brain health public events

The SENSE-Cog team at Manchester were at the Brain Health and Active Ageing information event in Stockport, Greater Manchester, on 3rd October 2019. This was the first time Stockport Council, Stockport CCG, Pennine Care Trust, Life Leisure and Age UK Stockport have held an event focussing on Brain Health for the people in Stockport. The event was attended by over 120 people. The feedback from those who came was very positive. It was a good opportunity for the SENSE-Cog team to recruit people to take part in the research. The SENSE-Cog team used Virtual Reality headsets to show people what it was like to have a visual impairment.



Photo caption: Busy day at Stockport Brain Health and Active Ageing event

The Manchester SENSE-Cog team were also at the Alzheimer's Research UK Public Engagement Event on 24th October 2019. The event was held at the Manchester Science and Industry Museum and visited by over 800 people. Visitors of all ages spoke to the SENSE-Cog team and tried out hearing and vision tests. Visitors had the opportunity to test the Echecker and were positive about its applications and relevance for people who are concerned about their cognitive, vision or hearing health. Younger visitors tried the VR headset to see how things look like for people with visaul impairments, and were also challenged with task to complete some items of the MoCA test such as the cube drawing and clock drawing with the VR stimulated visual impairments. Younger visitors also engaged in making brain hats to help to them understand the functioning of the brain.



Photo caption: Saima Sheikh and volunteer Jennah Miah ready to engage with public members and to raise awareness about SENSE-Cog.

### A big 'Thank you!' to our Research User groups



Photo caption: Manchester Research User Group (RUG) members and SENSE-Cog researchers come together to celebrate the work and contributions made by group members over the past four years.

After four years of dedication, the RUG's involvement in our work comes to an end. A series of 'Thank You!' events are taking place in Manchester, Nice, Nicosia and Athens to formally thank people for their ongoing contributions and for sharing their life experiences which motivated their involvement with the SENSE-Cog project. At each 'Thank You!' event, the research team will present the results from the work so far, as well as explaining how the advice from the RUGs influenced the work.

### Feedback from researchers on the impact of working with the RUGs:

"It helped us as a research team because having participants that were able to ask helpful questions, in a way nudged us to be more precise in explaining about the project."

"It is hard as a researcher who doesn't really have any experiences of the problem to understand the meaning of the problem for people, which obviously can make it difficult for us to always know what priorities we should set or whether our direction is relevant. So yes, it's given us a different perspective on our work."

"I think it's very useful and I think it gives a perspective to research that we needed to have, because we kind of tend to, you know, sort of take the feeling out of our day to day research and when you have the actual patients explain to them rather than peers, it does give us a different perspective."

# Fourth SENSE-Cog General Assembly 2019 meeting in Dublin hosted by the Global Brain Health Institute



The fourth annual SENSE-Cog project meeting took place from 9 - 10th October 2019 in Dublin at the Global Brain Health Institute at Trinity College. The researchers reviewed progress with the research and planned for the successful completion of the SENSE-Cog project. Well done to our international team on another successful General Assembly meeting! Amazing progress achieved so far!

### Meet the team @ Athens



Photo caption: (from the left) Maria Passa, Evgenia Katirtzoglou, Antonios Politis, Evangelia Stamouli, Evangelia Kontogianni. (Photo on right) Maria Alexaki.

#### **Antonios Politis**

Professor of Psychiatry at the 1st Department of Psychiatry, "Eginition" Hospital of National and Kapodistrian University of Athens (UoA), Director of the Division of Geriatric Psychiatry (DGP).

### **Evangelia Stamouli**

General Practitioner, Doctor of Biochemistry of the Medical School of the National and Kapodistrian University of Athens. Evangelia is an external scientific associate at the Division of Geriatric Psychiatry at the 1st Department of Psychiatry, "Eginition" Hospital of UoA.

#### Maria Passa

Social Worker at the Division of Geriatric Psychiatry at the 1st Department of Psychiatry, "Eginition" Hospital of UoA. Maria has been trained in Psychotherapy in elderly patients with depression as well as in Cognitive Behavioral Therapy and received a MSc in "Mental Health Promotion-Prevention of Psychiatric Disorders".

### Evgenia Katirtzoglou

Psychiatrist and a clinical research fellow at the Division of Geriatric Psychiatry at the 1st Department of Psychiatry, "Eginition" Hospital of UoA

#### Maria Alexaki

Social Worker with an MA in Social Work Studies. Maria has worked with diverse populations in community health care, outpatient and inpatient treatment settings.

### **Evangelia Kontogianni**

Psychologist with MSc in "Mental Health Promotion-Prevention of Psychiatric Disorders" trained in Cognitive Behavioral Therapy.

### **Notes for Athens Research User Group members:**



"Our meetings are being held in a pleasant and friendly environment. We all participate and we all feel the need to express our opinions and comment in order to help the aims of the research. We follow the instructions and we try to reply to questions through discussion and with the necessary clarifications given by the coordinators. The time given to us [for all these] is sufficient. I express my satisfaction and joy for participating in this program. I learn and I keep learning how important is my participation in a team that elaborates common issues and the needs of elderly people seeking a good quality of life. Getting in contact and meeting experts is important to me. I get to know more about the difficulties in caregiving for people living with dementia and its consequences. The program also gives us the chance to get to know more about the use of technology in hearing and vision impairments. Special thanks to the coordinators that gave us the chance, in each meeting, to work on the necessary material with ease and pleasure."

"When it comes to the SENSE-Cog program, as we get to know it, I could say that it was a chance for us to learn about the ways to communicate and deal with people with cognitive, hearing and visual impairments. Apart from the knowledge we gained, maybe the most important thing about it, it's the participation in this team, of the people living with these impairments. I think that the fact that they shared thoughts and feelings, gave us, caregivers, the ability to recognize the difficulties they experience and the impact those impairments have on their daily life and on their social life. I feel that as a participant of this program, this process open my eyes for the living circumstances of my own people and I was given useful guidelines as to how I can better and more efficiently understand and deal with their daily life, and how I can be present (in their lives) in a more effective way."

### **Publications of interest**

- Patient and public involvement in dementia research in the European Union: a scoping review. <a href="https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-019-1217-9">https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-019-1217-9</a>
- Vision loss and 12-year risk of dementia in older adults: the 3C cohort study.
   <a href="https://link.springer.com/article/10.1007%2Fs10654-018-00478-y">https://link.springer.com/article/10.1007%2Fs10654-018-00478-y</a>
- Hearing interventions to prevent dementia https://link.springer.com/article/10.1007/s00106-019-0617-7
- Feasibility of an Intervention to Support Hearing and Vision in Dementia: The SENSE-Cog Field Trial. \*https://onlinelibrary.wiley.com/doi/full/10.1111/jgs.15936

### Connect with us!

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