



SENSE-Cog Internal Newsletter

July 2016

Greetings SENSE-Cog Team!

This is the first of our regular project updates. We hope you will contribute to its contents as the study progresses. As you all know, we opened the SENSE-Cog programme on 1 January 2016 and are now nearing our first 6 month-point of activity. Much has happened since our kick-off meeting at Old Trafford in February.

UK votes to leave the EU! But SENSE-Cog will keep calm and carry on:

The Brexit result was a great personal shock and disappointment to very many of us. But the result does not affect our resolve to continue to work with our colleagues across Europe for the benefit of all European and global citizens.

The future may be uncertain. But SENSE-Cog and other currently funded Horizon 2020 projects will continue. EC Commissioner Carlos Moedas stated (27 June 2016) "Until the end of the negotiations, UK remains Member of the EU and therefore with all the rights and obligations, including in relation to Research Programmes like Horizon 2020." The UK government has confirmed this position: "The referendum result has no immediate effect on those applying to or participating in Horizon 2020...The future of UK access to European science funding will be a matter for future discussions. Government is determined to ensure that the UK continues to play a leading role in European and international research." (Jo Johnson, UK Minister of State for Universities and Science, 28 June 2016).

WP 2/3 Expert Reference Group (ERG) under the olive trees in Athens!

Our team from Nicosia hosted a busy two-day meeting for experts in Athens in April. It was organised by 5 members of the WP 2 and 3 teams (Chryssoula Thodi, Pavlina Charalambous, Lucas Wolski, Iracema Leroi and Piers Dawes) and welcomed 12 expert professionals from London, Wales, Canada, Athens, and Crete to discuss various issues pertaining to the assessment and management of hearing and vision impairment in dementia. We had prototype case discussions in break-out groups, individual presentations about the experts' perceived 'gaps and solutions' in the field, guided group debates about the threats and opportunities of different intervention implementation procedures, and a 'dissection' of a commonly used cognitive assessment battery from the perspective of those with hearing and vision impairment. We captured the views and opinions by audiotape, all of which are now being analysed by Ines Himmelsbach and Lucas in Freiberg so that the content can guide further WP 2 and 3 work. We had a lovely Greek meal in the city centre at the end of first day.

Site visit to the University of Bordeaux:

On behalf of WP 3.1, the development of the intervention for the RCT, Iracema and newly appointed-RA, Annie Pye, visited the team in Bordeaux. The day-long visit was hosted by Catherine Helmer and her clinical team as well as the members of EUCLID. Preparations for the soon-to-start support care needs' assessment were made. The time line of RCT preparation activities was discussed with the

EUCLID team, and aspects of the intervention protocol were debated. Annie and Iracema were also able to catch up with Cécile Delcourt from WP1 who reported that contact with the Rotterdam team has been made and early work on the datasets for WP1 has begun.

We will be back to Bordeaux in September for the WP1 team meeting, followed by a day-long SENSE-Cog Steering Committee meeting. Annie and Iracema enjoyed pasta with cèpes and foie gras, nicely paired with a fruity Bordeaux red under a 12th century arch.

Health economics post-doc off to a flying start:

Fan Yang has arrived from Singapore to take up the post of research associate for WP4, working with Brenda Gannon. Their first task is a systematic literature review of health economic measures relevant for dementia. This paper has been submitted to the Society for Medical Decision Making North American Meeting, which will be held at Vancouver, Canada, on October 23-26, 2016.

Focus group training in Manchester:

Lucas Wolski conducted training in qualitative methods for Manchester and Bordeaux RA's for the qualitative work in WP 3.1. Training took place on June 6 and 7 and included a side-trip to Manchester's curry mile (but sadly, no football games).

ARTTIC takes over from GABO:mi as project managers:

Sadly, GABO:mi went into administration and will no longer be working as a partner in SENSE-Cog. We wish our lovely project co-ordinator Kathrin Prebeck all the best and many thanks for her excellent care of SENSE-Cog during the application and set-up of the study.

Following a consensus vote by SENSE-Cog members, European project management company ARTTIC has taken over participation in WP5 and WP6 from GABO:mi. Our new ARTTIC team members are senior project manager Richard Moore and project manager Sylvia Cucinelli. Welcome!

Piers travels the world as SENSE-Cog ambassador:

Piers Dawes has been spreading the SENSE-Cog message far and wide with trips to meetings in Australia (Audiology Australia conference in Melbourne and Seminar at the Australian Hearing Hub at Macquarie University in Sydney), Belgium (BAudio conference in Antwerp), the UK (British Society of Hearing Aid Audiologists Congress in Nottingham and a Manchester University Faculty Talk). Piers will give keynote talks about SENSE-Cog at the International Hearing Aid Conference in California in August and at the South African Association of Audiologists Congress in Johannesburg in October.

Research User Group (RUG) updates:

Jahanara Miah, Suzanne Parsons and Piers, have been busy getting the WP5 activities underway.

Kerin Bayliss has been recruited as the Patient and Public Voice (PPV) co-ordinator for Manchester and Alexandra Konig will join from Toronto in September as the PPV co-ordinator for Nice, and the PPV co-ordinator for Cyprus will be confirmed soon. The role of the PPV co-ordinators will be to establish and manage the local Research User Groups (RUGs), deliver research awareness training to equip the RUG members and familiarise the RUG members to the SENSE-Cog project.



Discussions are underway with Professor Karina Lovell to design the Research Awareness Course training. The Course will be adapted by the WP5 team to ensure the course is engaging and appropriate for RUG members' language, culture, and age, cognitive and sensory disabilities and to empower RUG members to take a meaningful and active role in the SENSE-Cog project.

Jahanara and Kerin are in the process of recruiting members for the research user group in Manchester (see flyer), we are looking for up to 5 people with lived experience of dementia/ memory problems and hearing and/or vision problems or their carers to help the SENSE-Cog team shape research to find the best ways of identifying and supporting older people with hearing, vision and memory problems.

To date we have had patient public involvement (PPI) on the Support Care Need Survey (SCNS) for Sensory and Cognitive Health and the Sensory Support Care Preferences Questionnaire. MICRA has helped us with the set-up of a focus group to advise us on the best ways to involve the public in the SENSE-Cog project on dementia, hearing and vision loss and advise on the relevance, wording, suitability and appropriateness of the RUG recruitment flyer.

Website construction underway:

Currently, the content for the website is being collected from the Participants which will have to be adapted into the website, to give a general overview of the project and the targeted benefits for the public. Should any Participants have any further ideas for content or have supplementary material that could increase the public's interest, please do not hesitate to send this to Piers!

Website development will be done by our new management company ARTTIC, who took over project management from GABO:mi in July 2016.