

SENSE-Cog Asia News



Issue 1



Welcome!

To address the global health priority of neurocognitive aging, including the rising prevalence of co-occurring age-related cognitive and impairments in older people particularly in low and middle income countries.

Dear Reader,

Welcome to the first newsletter from the SENSE-Cog Asia project. SENSE-Cog Asia is a six month feasibility study that started in March 2019 and is funded by The University of Manchester's international 'Global Challenges Research Fund' in the UK. The study is coordinated by The University of Manchester (UK) with three South Asian countries: Pakistan, India and Bangladesh.

The project is 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: intervention development in the European SENSE-Cog programme (for further information visit <https://www.sense-cog.eu/>).



The potential to extend this approach to low and middle income countries (LMICs) is great and will enable the utilisation and adaptation of existing resources and infrastructures to support research and care pathways for dementia and sensory health in South Asia.

The project newsletter, intends to keep you updated on the ongoing activities of the SENSE-Cog Asia project and related activities. Your feedback is very welcome.

In this issue:

- Publications of interest
- Project background
- Progress to date
- Patient and public voice
- Meet the team

Publications of interest

- Individualised sensory intervention to improve quality of life in people with dementia and their companions (SENSE-Cog trial): study protocol for a randomised controlled trial.
<https://trialsjournal.biomedcentral.com/articles/10.1186/s13063-018-2973-0>
- Assessing and managing concurrent hearing, vision and cognitive impairments in older people: an international perspective from healthcare professionals.
<https://academic.oup.com/ageing/advance-article/doi/10.1093/ageing/afy183/5272748>

Project background

There is a worldwide increase in aging-related neurodegenerative conditions which lead to dementia. Age-related hearing impairment is also highly prevalent (>90%) in people with dementia, with the majority of people with dementia worldwide currently living in low and middle income countries (LMIC). However there are limited services to support age-related health issues and limited health support seeking behaviour due to a lack of awareness of dementia as a health condition amongst the general population, as well as significant stigma associated with a diagnosis of dementia. Therefore interventions that improve hearing function may delay cognitive decline in dementia and improve quality of life for patients and caregivers.

The feasibility study will evaluate the feasibility and acceptability of potentially low cost, easy-to-use and home-based intervention designed to detect and support people with dementia with hearing impairment. With an aim to improve outcomes in older people with dementia and hearing impairment and their care partners, in a LMIC setting (India, Pakistan and Bangladesh).

The intervention 'Asian Supportive Hearing Intervention for Dementia' (ASHID) is an eight week home-based intervention delivered by hearing support practitioners. The total duration of the study including baseline and follow up assessments will be 18 weeks.

Progress to date

The study has already received favourable ethics approval from University of Manchester and currently in the process of training the staff and setting up the study in the following seven sites across India, Pakistan and Bangladesh:

- National Institute of Mental Health and Neurosciences Bengaluru (NIMHANS)
- Schizophrenia Research Foundation Chennai (SCARF)
- All India Institute of Speech and Hearing Mysuru (AIISH)
- Sir William Beveridge Foundation Dhaka (SWBF)
- Pakistan Institute of Living and Learning Karachi (PILL)
- Pakistan Institute of Living and Learning Lahore (PILL)
- Pakistan Institute of Living and Learning Rawalpindi (PILL)

Updates from Bangladesh: Thank you to Dr Mo Sakeel and Dr Biswash for hosting a great event to inform stakeholders in Bangladesh about the 'Asian Supportive Hearing Intervention for Dementia' project.



Training delivery: Dhaka

Face-to-face training delivered by Iracema Leroi (chief investigator) and Jahanara Miah (patient and public voice lead) covered: roles and responsibilities of principal investigators, research assistants and hearing support practitioners. Study protocol explained and discussed issues on policies and procedures. Important issues surrounding safeguarding when working with people with dementia, communicating with people with dementia and methods for assessing capacity and ensuring informed consent. Training with other sites was delivered over video conferencing, with real-time presentation slides.

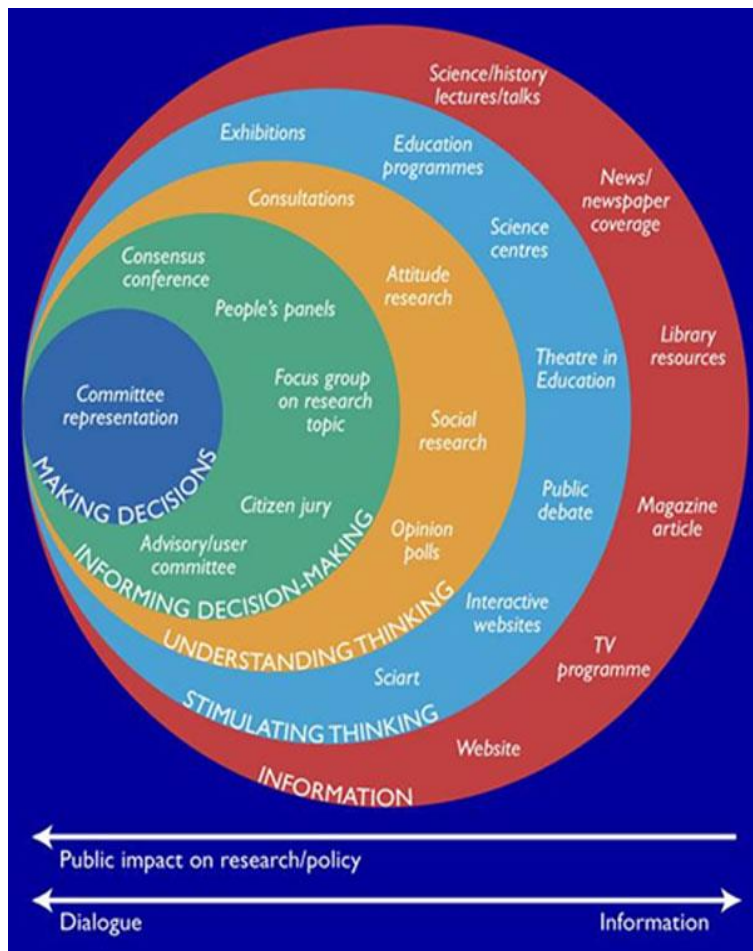
Study Launch event: Dhaka

A successful launch event attended by 100 delegates was held in partnership with Renaissance Hospital & Research Institute Ltd, Hearing Care Centre Ltd, Bangladesh and Sir William Beveridge Foundation on 9 March 2019 to support the SENSE-Cog Asia feasibility study. The discussions were lively and provided a platform for key stakeholders to have a dialogue about dementia and hearing impairments that have not previously been discussed in such settings. Delegates went away with some great points to think about and take up with colleagues, and key contacts to build working relationships.

Knowledge, Attitude, Practice: Dhaka

In the data collected from the Dhaka event launch, a wide range of experienced professionals responded to the SENSE-Cog care home Knowledge, Attitude, Practice (KAP) survey, including doctors, medical students, occupational therapists, social workers and physiotherapists. When completing the survey, the majority agreed that the cost of sensory aids is problematic for people with dementia in Bangladesh, whilst a lack of understanding of the illness presents barriers in supporting people with dementia. As a result of the latter, over half of the respondents commented that there is a need for specialised training in both dementia and sensory impairments in Bangladesh.

It's about us - patient and public voice (PPV) in Bangladesh, India and Pakistan



Local sites are identifying interested individuals to set up patient and public working groups consisting of older adults with dementia and /or hearing problems, formal caregivers and family members of affected person, older adults support groups, charities, and service providers. The purpose of the patient and public working groups will be to act as a critical friend in advising the research teams in undertaking the feasibility study. The principle of patient and public voice is about people affected by a condition, or the wider public that are affected by health research, having a right to have a say in decisions about research that may affect them.

Involvement activities of the patient and public working groups will cut across the various layers, demonstrated in the 'onion model' (Wellcome Trust: 2002) on the left. The red and blue rings are engagement activities that address larger audiences such as programmes, websites, and articles in newspaper or magazines, and education programmes. The inner layers of the onion, the orange, green and blue, are involvement activities which may reach smaller audiences, but the impacts are much greater. The approaches will be decided by each local site according to the needs and preferences of the patient and public working groups.

More information on patient and public voice in our European SENSE-Cog EU can be found on <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-018-0128-9>

Dr Vaishnavi Ramanujam visits SENSE-Cog team in Manchester (UK)

On 13 May Dr Vaishnavi joined up with the SENSE-Cog team at Manchester to talk more in detail about the plans for the study in Chennai site. She met with Emma Hopper (Senior Sensory Support Therapist and trainer), Saima Sheikh (UK Study coordinator) and Jahanara Miah (PPV lead). Dr Vaishnavi found the meeting useful. She commented:

“This face-to-face meeting is so much better, than video-conferencing. It helps to build a better relationship with the team here, on the video-conference we just cover the items on the agenda. But we have had so much to talk about, and also used this opportunity to clarify things that were a bit unclear”.



Dr Vaishnavi is also spending six weeks at Dundee (NHS Tayside) observing old age psychiatry practices in dementia care. The Chennai team have big plans to set up an in-patient dementia service in Tamilnadu. Dr Vaishnavi plans to take back her learning to transfer knowledge on in-patient service focusing on models of best practice and pathways of care for people with dementia and to improve the knowledge with the wider team in Chennai.

Meet the team @ Manchester (UK)

Chief investigator - Professor Iracema Leroi

Professor Leroi is the lead Investigator for SENSE-Cog. She trained in Canada and at Johns Hopkins University School of Medicine in the USA.

Chief investigator – Professor Nusrat Husain

Professor Husain is Director of Research Global Mental Health at Division of Psychology and Mental Health at UNIMAN. He has a keen interest in addressing the huge treatment gap in low and middle-income countries.

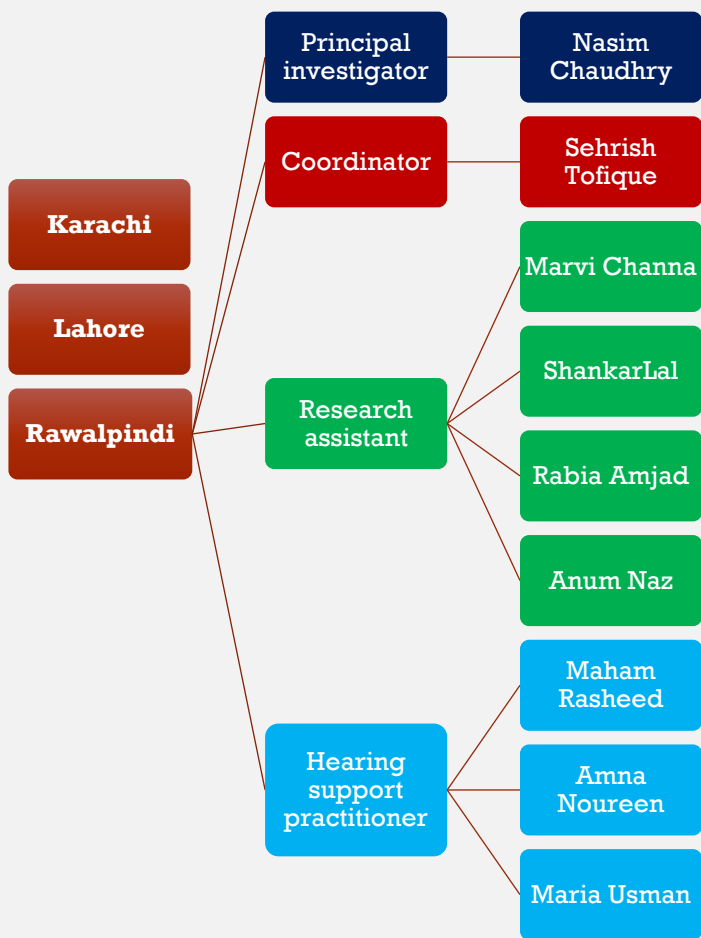
Project coordinator – Saima Shiekh

Saima is currently working on SENSE-Cog EU project on validating cognitive assessment tools for people with hearing and vision impairment. She has a keen interest on improving quality of life of older people.

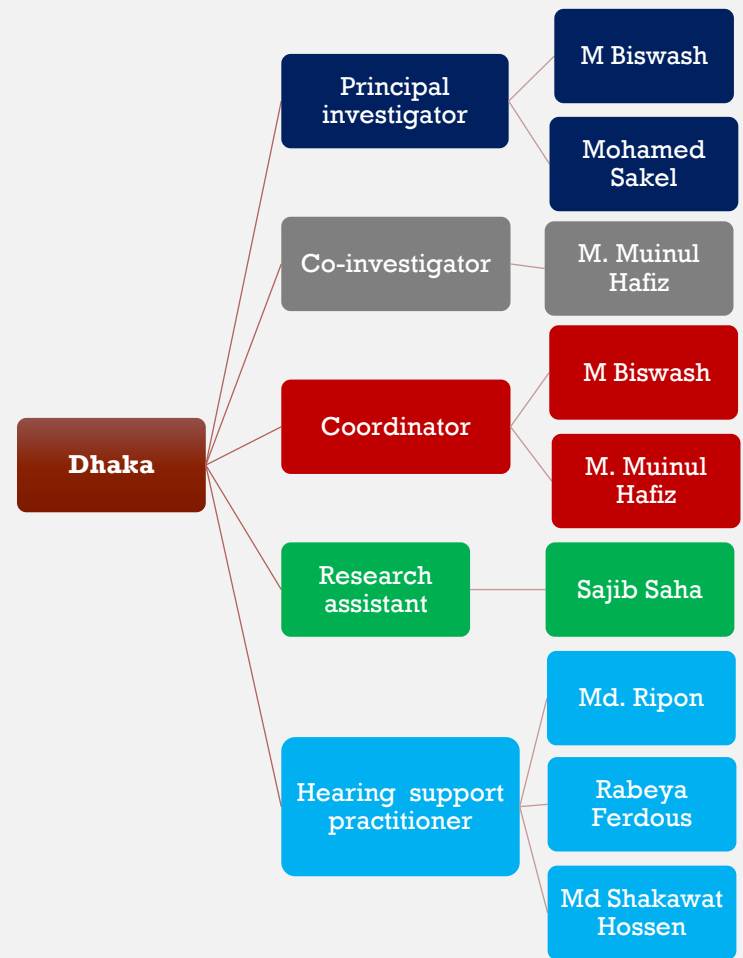
Patient and Public Voice (PPV) lead – Jahanara Miah

Jahanara works with the team at the Division of Neuroscience and Experimental Psychology on the SENSE-Cog project, with a specific focus on streamlining PPV in dementia research.

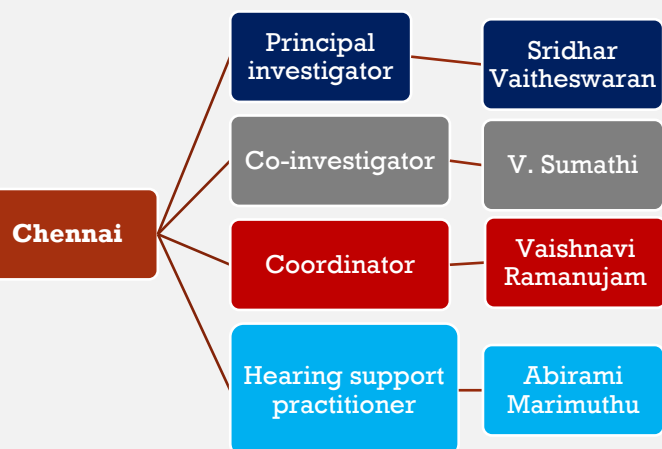
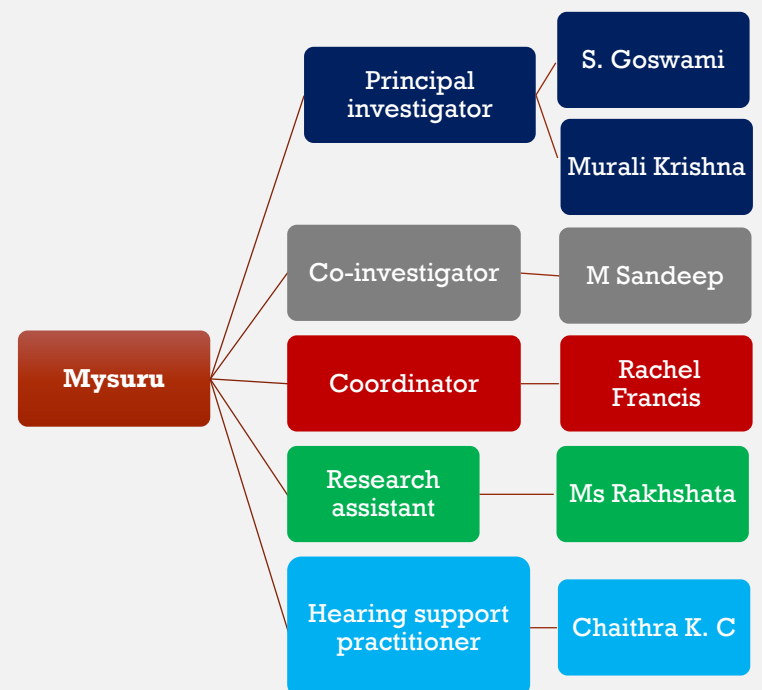
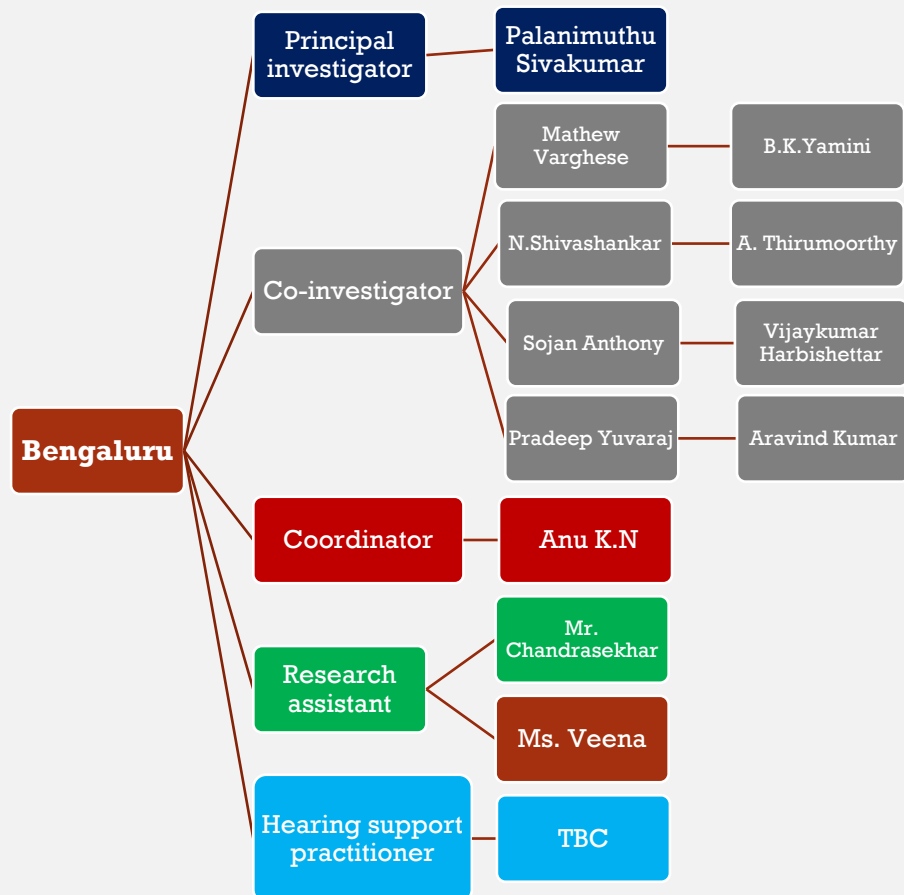
Meet the teams @ Pakistan



Meet the team @ Bangladesh



Meet the teams @ India



If you have any news for the next issue of SENSE-Cog Asia News, please contact jahanara.miah@manchester.ac.uk