# NIHR Dementia Global Health Programme (DePEC)

# Team Workshop, Tanzania – 11-12 March 2019

Attendees: Louise Robinson (LR); Susan Hrisos (SH); Emma McLellan (EM); Michaela Goodson (MG); Devi Mohan (DH); Thomas Iype (TI); Biju Soman (BS); Sanjeev Nair (SN); Matthew Prina (MP) Richard Walker (RW); Stella Paddick (SP); Declare Mushi (DM); Ssenku Salic (SS); Marcella Joseph (MJ); Beatrice Temba; Dr Damas.

### Day 1

LR welcomed everyone and introductions were made around the table, an overview of the programme was also given by LR.

**SH and MG gave a presentation on WS4 (slides attached).**

LR is mindful of ethical approvals within each partner country and that the speed and flexibility of the process can be complex. Ministry of Health ethics will be much more difficult to get, and it’s hoped the new classification of potential participants, especially professionals, will make it easier to use university ethics i.e. if there is a university employed/attached person involved in clinical/policy work university ethics would be required. Interviews will begin with professionals.

A group discussion about how the qualitative study would work in each country followed. A key issue identified for each partner country is the need for earlier presentation/diagnosis. People currently present late as i) their spouse compensates for the pwd ii) the family provide a good support system and iii) there is high use of traditional healers before medical presentation.

There is no care pathway in India, the team there are interested in families/family carers and how they cope and are keen to focus on patient and family coping strategies.

Faith healers and traditional medicine were highlighted as something of interest to be included in the qualitative study. SP informed that she had previous involvement in a pilot in Tanzania to interview faith healers; MG said that there were different kinds of faith healers dependent upon beliefs in Malaysia; the Kerala team agreed patient belief systems were very important.

Each partner country had a small group discussion about how the qualitative research would work, and considered their own sampling frame referring to the Malaysia list presented in WS4 slides. Feedback from the groups included:

Tanzania (emphasised need to include people who actually have something to with dementia)

* *Sampling frame –* see attached slides completed at workshop.
* *Ethics –* will need a minor amendment to existing ethics (local ethics should take around 1 or 2 months); national ethics will involve a charge and will probably need to be chased up weekly (process likely to take 3 or 4 months); preparatory activities and pilot study could be done with local ethics before national ones come through.
* *Resources –* have people who can do data collection (ideally Jane who is post doc and has done a lot of qualitative work). Main costs would be transport (logistics of rainy season need to be considered) and any transcription/translation.
* *Training –* qualitative training for the research team, including NVivo.
* *Timing –* June/July for pilot, Sept for full qualitative work.

Kerala

* *Sampling frame –* see attached slides completed at workshop.
* *Ethics –* local level shouldn’t be a problem, but may need government administration clearance which could take time.
* *Resources –* have people who can do the data collection, but would like some information to work with for researchers who need training (option of developing a webinar to be followed up **SH**).
* *Training –* qualitative training for the research team, including NVivo (would probably prefer site visit). Also clinical training aspect to consider, professional groups may attend talks on dementia or be interested in training on cognitive assessment.
* *Timing –* ethical approval at local level could be done in the next few months, if further ethical approval required could perhaps be in place by Sept – suggested pilot study could be presented at Sept meeting.
* *Issues –* concerns about negative connotations and sensitivities around exposing weaknesses in the system, will need to be presented from a positive perspective e.g. an opportunity to develop something.

Language was highlighted as a potential issue (more so with families) for the qualitative research in each country, as was translation. Transcription and translation/back translation needs to be thought about (**SH** to consider consistency protocol).

**DM gave a presentation on WS3 (slides attached).**

DM confirmed that WS3 has university ethics and they believe they can recruit 120 participants, the possibility of evaluating a timed cognitive test is to be looked into further. The team were asked their thoughts on when to exclude people from the study in relation to some drugs affecting salt levels, ideally participants wouldn’t be on medication. Responses included: retain people by checking drugs constant would be an option; capture drug details throughout data collection; include people who have been stable on medications for three months.

**SP gave a presentation on WS2.2 (slides attached).**

LR queried what skills would be needed to be trained to use the app. The app would not necessarily require a Dr to use it, but the person would have to have clinical experience. Key to this experience would be assessing elderly people from this perspective e.g. psychiatric nurse, OT, psychologist. SP confirmed that training is definitely needed. A training workshop has been held in Kerala but maybe more in the field/practical/hand holding support will be needed as perhaps not everyone picked up the same skill level from the training.

SP also informed the group she had a meeting planned with someone from the Ministry of Health to talk about care of older people work, and to help devise treatment guidelines for dementia.

**The Kerala team gave a presentation on progress (slides attached).**

MG queried whether the same process for the app would be happening in Malaysia, and thought it might work better in secondary care there. It was confirmed that the purpose of the feasibility was to see if the app needs to be changed/amended for the different countries, and it was agreed that cultural context needs to be considered for the app. With regards to the protocol for this work Malaysia and Kerala will be most similar so Kerala will forward their protocol to help MG move forward with ethics.

Findings of Kerala’s study into use of NICE guidelines will be forwarded to SH to see if there is any relevant input for WS4.

**MP gave a presentation on WS2.1 (slides attached).**

MP informed the group that there had been some delays due to BS maternity and CvA leaving, but work is now back on track. There may be a need for some extra resource for screening but this will be discussed with BS in a few weeks. It’s possible there may be students able/interested, or perhaps SH/EM may have time.

There was some discussion around use of the term mild cognitive impairment (MCI). Kerala would usually use dementia but MCI is also used, MCI probably isn’t used much in Tanzania.

### Day 2

**LR gave a presentation on the MOOC (slides attached).**

The group were asked whether a MOOC would be something that would work in the partner countries. Each country team were asked to consider: what is currently available for carers; if the MOOC would be useful; are their people within their networks who would be interested in signing up to the MOOC. Feedback from the groups included:

Malaysia

* Adaptions may be needed for language, culture and content.
* Community forums tend to be English speaking and people from other countries may not be confident enough to engage with them.
* The MOOC could be tried out by a few post docs, feedback could perhaps be formalised and create an evaluation (could probably be done for both MOOC, wouldn’t be a huge effort but focussing on other WS tasks for now).

Tanzania

* The first MOOC has been completed by a member of the Tanzanian team.
* Possible issues around language and access to the internet.
* Training material is based on carers in the UK and care homes are just for people with no family, adaptions would be needed.
* Swahili videos would be better, as would the inclusion of people from Tanzania – examples of people actually living in the situation i.e. a rural person in Tanzania.
* Healthcare workers may have access to the internet, but for rural areas a video to watch would perhaps work well – the course could be accessed/watched in rural dispensaries or churches rather than online.
* SP has developed a carers package, the MOOC could be linked in.
* Could be useful to try and link MOOC to guidelines to make it practical.

Kerala

* Think there is a need for something like the MOOC as don’t have any other programme – could be relevant for family, staff (nurses, researchers, Drs) and other groups (senior citizen associations).
* Needs to be user friendly for carers and language may be a problem – subtitles may help as accents can be difficult even when people can speak English.
* Team are interested in short term (strengthening carer programmes) and long term (working with communities) training packages for the future.
* Interested in looking at both MOOC.
* Could also include information on short term and long term memory changes or different effects on memory and functionality.

\* **LR** to find out when MOOCs will run again. *Dementia Care: Staying Connected and Living Well will run from 8 April 2019; Dementia Care: Living Well as Dementia Progresses began 18 March 2019 and learners can sign up to the course for the following six weeks, it will run again (possibly Sept/Oct) but dates are to be confirmed.*

The following group discussion highlighted that religions and attitudes towards dementia will differ in the partner countries, which may influence training. There isn’t much training for staff in Kerala and Malaysia on dementia and geriatrics. LR informed the group there was a range of training/learning for professionals available through BMJ learning which would be worth looking at for healthcare staff. It was suggested that a mapping exercise to see what current educational resources are available for professionals around older people/dementia care would be helpful (**SH/EM** to follow up).

The workshop moved on to partner country group discussions around a work plan for the next four to six months, considering specific outputs and up to three key things they would like to achieve by the end of the project. Feedback included:

***Work plan for next 6 months***

* Malaysia

WS1 – stakeholder paper drafted and hopefully submitted by next meeting.

WS2 – pausing for the moment but probably up to point of access by next meeting; protocol needed from TI to adapt then test, exploratory work and submitting ethics; consideration of validation for app.

WS3 – first draft of systematic review (nutrition); baseline data collection ongoing, should be done by next meeting.

WS4 – focussing on this first; 3 ethical approvals should be fairly straightforward; finish care providers and facilitators data collection and perhaps some analysis by next meeting; need to look at funding for data collection resources.

* Tanzania

WS2 – validation of app should be finished by May (rains dependent).

WS4 – waiting for topic guide then have someone in mind to do data collection for the pilot; need to check funding for data collection work; get ethics in place; possible preparatory visit from UK researcher.

* Kerala

WS2 – app testing in two phases i) diagnostics, 30 mild to moderate pwd, 30 people who see psychiatrist with depression, 30 normal with everybody seen and assessed blind – will take 3 months and data complete by Sept ii) analyse data, then 140 consecutive sample patients will be screened blind and TI will do an assessment on each – will take 3 months and data complete by Jan (maternity cover needed for this phase); MOCA and prevalence papers to be submitted by next meeting; MOCA require statistical modelling training; systematic review underway but require skills training in meta-analysis.

WS4 – paused until WS2 work sorted.

***Capacity building***

* Malaysia

Support in running trials and data management.

Qualitative analysis, NVivo.

Keen to have clinical dementia training for Drs/MOs.

* Tanzania

Potential fellowship/scholarship for MJ.

Masters for SS based around work he’s been doing, and possible online courses.

PhD on carer interventions for SM.

Dr Damas could do some WS4 interviews, possibly MPhil neuropsychology and ultimately a PhD.

\*LR would like a summary of all students and potential masters.

* Kerala

Qualitative research skills and NVivo training.

Statistical analysis.

***Outputs***

* Malaysia

Integration of care, reasons to work together i.e. faith healers etc.

Online training for carers and care professionals.

Feasibility and resource mapping for ongoing work.

National networking event, perhaps link with new guidelines.

* Tanzania

Capacity building.

Sustainability of new Alzheimer’s society.

Discussion of dementia policy and dementia added to guidelines.

Wide use of app.

* Kerala

Care pathway for the elderly, including cognitive decline.

Perhaps guidelines.

Additional comments included:

* A six month no cost extension may be worthwhile for wider dissemination. LR attending NIHR national meeting in early May and will know more then.
* PIs to start thinking about accessing smaller pots of money to continue work.
* PhD students can’t be funded by the project but training support/attending meetings will be considered on a case by case basis.
* All capacity building/outputs from the project need to be recorded, everyone to let TL know about papers, posters, PPI etc.

**SH/EM ran a qualitative research training session (slides attached).**

Before the end of the workshop future group meetings were discussed and Dubai was suggested as a location for the next meeting (30 Sept/1 Oct) to help even up travel time for all partner countries. A date for the following group meeting in Kerala was agreed, Jan 28/29 (Jan is tourist season which will affect costs earlier in the month). There is also the possibility of a team meeting to coincide with the Alzheimer’s International conference in Singapore March 2020, to be discussed further.