NIHR Dementia Global Health Programme (DePEC)

Programme Meeting & Workshop, Kerala – 28-29 Jan 2020

Attendees: Michaela Goodson (MG); Susan Hrisos (SH); Emma McLellan (EM); Thomas Iype (TI); Biju Soman (BS); Sanjeev Nair (SN); Dr Sreelakshmi (DrS); Veena Babu (VB); Divya Nair (DN); Ravi Prasad Rama (RPR); Dr Vijayakumar (DrV); Raman Kutty (RK); Stella Paddick (SP); Jane Rogathi (JR); Sarah Mkenda (SM); Devi Mohan (DM); Tan Maw Pin (MPT); Roshaslina Rosli (RR).

Day 1 AM

MG welcomed everyone and introductions were made around the table, apologies were received from LR who was unable to make the meeting due to clinical responsibilities. The group were informed that the NIHR no-cost extension had been successful, but the additional year of funding for a costed extension had been rejected due to limited evidence of how the LMICs would benefit. MG then set out the aims of the workshop and what was hoped to be achieved, then talked through the agenda.

Presentation: SH and MG (on behalf of LR) - Next steps (slides attached Depec -Programme Meeting Jan 2020 Ke**)**

The emphasis of the presentation was on future funding and preparation for funding calls. Providing an evidence base of what each LMIC partner actually needs, and being able to demonstrate the work required is considered a very important next step. As an example, there was a discussion around the implementation and logistics of CST, and whether there is an evidence base to say we need it. SP pointed out that CST works, but that there is a published adaption of it so does it need to be done again? There could also be an issue with the longevity of CST and what happens after sessions are completed. However, CST is effective and relatively low cost so there could be potential to expand into other locations. Specialist nurses are currently doing CST therefore skilled people would be needed to deliver it. Also economics, training and who does what needs to be considered, and an evidence base to support a strategy is required. MG pointed out that the length of a grant will also influence what can be done, work would be limited for a 1 year grant but more could be done over 3 or 5 years. Including additional extras like health economists and comparisons with existing strategies could also be advantageous for future funding.

Presentation: TI - Systematic review (slides attached Thomas Iype_2020_01_23_Pre**)**

MPT asked how the team were going to sort prevalence and meta-analysis, and offered to share some software information she had. SP replied that they may not be able to do meta-analysis and it was difficult to come up with a prevalence estimate due to geography. MG suggested presenting geographical data in regions could be best, and that it would be good to see where studies were placed on a map. This led to discussion around the ability to do meta-analysis with the tools used, and diagnostic criteria. The team want to show they have data but there are gaps due to too much heterogeneity, and there were concerns that if the meta-analysis was too clustered it may not be published. A further discussion around what other data may be available followed. The CFAS 1990's studies were mentioned as good examples to repeat and see if prevalence has changed, if it was repeated using the same tools what would you get? MG suggested there may be other information

available in journal articles, grey literature, census and/or household study data - the need to be careful not to duplicate data was highlighted. DM also informed that there was an ageing study of India (The data from LASI which could be used due to be published. TI concluded they expected the work to be finished in the next 3 months.

Presentation: BS - IDEA tool validation (slides attached Biju Soman_DePEC PPT IDEA Kerala.pdf **)**

Data has just started to be analysed and some interesting things are coming out. Phase 1 is completed with modifications and phase 2 in process, aim is for total of 200.

There was a discussion around interaction effects and presenting this as a regression - perhaps making a scoring system to risk. The most important variable could be rated with a score, and once the scoring system is developed it could be used in future for local practice or a possible new study. Logistic regression has previously been done in Tanzania, and a tool made using logistic regression could look at differences between Kerala and Tanzania. BS confirmed the team are very motivated to take the work further. SP said that in a busy clinic IDEA screening can be quite long so it would be good if it's possible to show the 10 word list could work alone, TI agreed this would be a simple test to use. SP also suggested the need for verbal fluency to have a suitable cut off for variations in different countries/geographical areas would be interesting.

Presentation: DrS - Normative data for MoCA (slides attached Sreelakshmi_The Indian normative da **)**

MG asked for clarification on the education and ages categories, is it the same nowadays or has it changed? RK confirmed that this has changed and in the last 20, 30, 40 years there has been more education. SP also said that in Tanzania in the past the very old did not have much schooling, but as they get younger most people have been to school.

A quick verbal update on WS4 work so far was presented: interview guides translated; ethics clearance from HAP; HMSC application in process (this only relates to data sharing); 2 pilot interviews completed; interviewers received training from Rema Devi S, a very prominent Social Scientist and qualitative expert in India.

A general reflection on the work being undertaken was the need to think about changes that are brought about within developing countries over time.

Day 1 PM

Presentation: DM - WS3 Nutrition study update (slides attached Devi Mohan DePEC meeting _ India Jan **)**

Screening is now complete and recruitment will have to stop in April, the study also has a later qualitative component. A small token has been given for each visit, with transport paid and refreshment provided. MG queried sending samples to Mario's lab and whether this would cause a time issue. DM replied that it can take time to get a MTA agreement so this was the best option,

MPT explained how she thought this agreement could be done quickly. The Gantt chart for this work is changing and the end of the study should be Oct, and the qualitative analysis will be mostly local. All of the processes for the study are set up so trials should be simpler in future. There has also been discussion around doing research in KK as it can affect recruitment due to perception/experience of KK, so this may be moved in the future, ie the strategy to increase recruitment is to have an additional data collection site.


DepEC Workshop Kerala_RR 28.01.20.p

Presentation: RR - Post-diagnostic dementia care (slides attached)

DrS queried what changes had been made to the topic guide, and whether the same guide would be used for all participants. It was explained that MG had piloted a topic guide using scenarios but that it had been quite repetitive and reached saturation quite quickly. It was also evident that the same topic guide didn't work with all participants. The original questions were rephrased and condensed to get more information from interviews, and more tailored topic guides were introduced for specific participant groups. SH confirmed this would be fully discussed at the site visit following the workshop, and that possible future adaptations would be worked through. It was also explained that the process can take a lot of time. An iterative process will be followed whereby a bit of data is collected then analysed, with any necessary tweaks made to the topic guide before collecting more data and repeating the cycle. In the Malaysia study the healthcare professionals (hcp's) reached saturation quite quickly so it was decided to look more at traditional healers. This led to a discussion around what was meant by traditional healers, and the difficulties of accessing and engaging faith healers in India. SH confirmed that including all alternative healers, both formal and informal, would be preferred and that the possibility of this could be discussed further at the site visit. MPT queried the timeframe for the next stage of Malaysia interviews, it was confirmed a site visit was being planned (to fit around the ADI conference) to fully prepare for this.


DePEC Jan 2020 Kerala WS2.2 updat

Presentation: SP - Dementia screening app development (slides attached)

The Ministry of Health in Tanzania have positively responded to the idea of dementia guidelines, as a result SP has been asked to develop a draft version. Keen to do stakeholder meetings for this but currently no funding for it, is it something that could be part of DePEC?

The IDEA screen has been validated and adapted in a number of places, perhaps something more collaborative could be done in the future. Suggested some follow up validation using named animals to see how they were given i.e. grouped, only animals in their local area or only animals seen in pictures. SP also highlighted the need to think about the amount of training required, and that there is a limit to what you can ask people to do when considering task-shifting. A dementia screening tool was developed prior to DePEC starting, a publication has been submitted but was rejected and needs to be re-submitted. SP suggested adding some depression screening questions to the updated version based on the screening tool development for depression. It was discussed whether this should/could be labelled as DePEC - the idea for the work and initial development/ethics proposal were all done before DePEC was put together but there are complementary aims for screening older adults which would fit with the DePEC aims.

Suggestion of an app to give advice for professionals. It was queried whether there could be additions made to the depression app to include advice at the end, or a what now step - what to do if suspect dementia as can't just do nothing. SP highlighted that she was concerned about people being referred for delirium - where are you going to refer them? The current app does not have case finding in it, agreement was made with the area MO for people to be seen so this could be further explored. It was also highlighted that it could be difficult to get people back for follow up, MG suggested this could perhaps be built in to CST to measure longitudinally and to see if people will respond to reminders. SP wondered if both follow-up and CST could be built into a later version of the App, possibly via text messaging. There is some initial data on delirium screening, but this has been published yet. WS2.2 have three papers completed.

Presentation: JR - WS4 update (slides attached 
Depec -WS4 Tz Update JR Kerala 28.**)**

It's been very difficult to get NIMR ethical approval organised, still waiting for an amendment letter from KCMCo before NIMR ethics can be submitted. Jane managed to get the approval letter from KCMCo during the programme meeting and the NIMR application was submitted the following day. , Though an expedited process will be followed to NIMR, it's still expected to take several weeks to process. The Gantt chart will need to be amended to accommodate for this. The pilot study has begun in Tanzania and 4 interviews have been completed, 2 traditional healers and 2 hcp's. SH confirmed the 4 pilot interviews will be analysed before work continues, and reiterated the iterative process of data collection then analysis before repeating the cycle.

Presentation: SH - Other areas of work (slides attached 
Depec -WS4 NCL Update SH Kerala 28**)**

It was confirmed that each partner country will have their own WS4 paper, and there will also be an overall comparison paper.

It's considered important to identify gaps in available guidance documents for dementia, and for each LMIC to collect information from anything found - a template can be developed for this. It was noted that documents may not be there, but we still need to look as this will help support an evidence base.

MPT asked about data protection and sharing, she was assured that the team follow GCP and all existing data protection management guidelines. This led to a discussion around research governance and sharing good practice. Personal data can't be shared and each partner should have their data stored in password protected documents. Data will need to be shared on a secure server, Google Drive could be an option and is what is currently being used with Malaysia. SP highlighted that for Tanzania ethics there was a section to complete on data protection and that a data transfer agreement was required. It was queried whether a data transfer agreement was required for fully anonymised data, the view was that it may be best to have the agreements in place. SP pointed out the current data transfer agreement is most likely with Northumbria so it would probably be best to get a new one with Newcastle, they're quite easy to get and should just involve a standard form. MG

suggested this is an area that will need to be discussed further for future work projects, and mentioned a management system used on another project which could be useful.

SH informed that LR's proposed plan was to continue moving toward a bigger network with the CST and STRiDE projects, and reiterated the need for evidence based ideas for our next steps. The group were then asked what they thought was important. There was a suggestion that an evaluation of CST using culturally appropriate comparatives could be explored. It was also suggested that there had been a change in the focus of what was being supported, with a move away from work on individual conditions to more general/multi-comorbidities (e.g. mental health in older people). BS suggested that interventions in broader areas or long term care pathways could be more appealing to funders. Themes that people can relate to are needed to gain public support in Kerala, and as dementia doesn't necessarily appeal at present a wider remit may work better. DrS highlighted a prominent diabetes programme currently running and suggested that links to this could be beneficial. Other possible difficulties associated with focussing solely on dementia included: nothing really available to treat pwd; busy clinics focus on people where a difference can be made, not necessarily ageing or dementia. Research outputs and implementation were also mentioned, with reference made to how there was very little evidence of this - another possible area to consider.

Day 2 AM

Good Financial Grant Practice (GFGP) preparation updates

Each Partner country presented for 10-15mins on progress & next steps following Theory of Change (ToC) development in Dubai.

GFGP-Rajmohan.pdf

Health Action by People (HAP) (Kerala partner)

Rajamohanan K Dr presented on GFGP preparation progress for HAP (slides attached). Several policies and standard operating procedures (SOPs) for research governance and finance have been created and ratified through HAP governance procedures and committees.

Current position: HAP have created an online GFGP application for accreditation at the Bronze level and have started to upload their documents to the system. They will submit when this process is complete. MG advised that they should claim the fee from the GFGP funding account and let us know once their Bronze accreditation is awarded.

Monash (Malaysia partner)

Devi Mohan gave a **verbal update** on GFGP preparation progress on behalf of the Malaysia partners. It is not possible to create an application for SEACO alone. There are several policies and documents available. However, the system is currently undergoing major change following which all processes might become decentralised (for Research Management and for HR). There are hundreds of versions of policy and the HoDs need to agree which policy will be used. This is a massive exercise for each separate policy. There is a need to convince those involved that this is a worthwhile

investment. The group reflected on the different experiences and challenges in preparing for GFGP accreditation for small (e.g. HAP) and large (e.g. Monash University) organisations

Current position: A decision needs to be made whether the GFGP application will be made at an organisational level or on a school basis. No decisions can be made until the end of Jan 2020.

KCMUCo (Tanzania partner)

Jane Rogathi and Sarah Mkenda provided a **verbal update** on GFGP preparation progress on behalf of KCMC. Jane explained the current approach to transfer and management of research funds for DePEC and other projects funded by Northumbria.

Currently funds for some projects are transferred to the 'HAI Northumbria' bank account, with the account managed by the 'HAI Northumbria' finance group. This arrangement was put in place for Depec funds due to the short notice of the grant submission. The accounts are audited each year by each project. Direct transfer of funds to a KCMCo university project account incur indirect/estates costs and 10% overheads and it was agreed that this should be factored in when costing future grants, so that the LMIC can develop and demonstrate accountability for financial governance and management. Mr Imani Israeli is the overall account manager. The GFGP accreditation is for KCMC only (and not HAI Northumbria).

Current position: Professor Declare is preparing a Bronze submission. JR will ask where he is with this and report back on: what are his plans to submit/ what stage he is currently at with this, and also what are KCMC plans/ what is now in place to enable direct transfer of funds. JR was asked to set up a WhatsApp group for GFGP.

NU MED /NCL University

MG reported that NUMED will aim for accreditation at the gold or platinum. Similar is aspired for NU Faculty level following discussions with Kings Gate, but this may need to be silver level depending on identification/availability of relevant current polices.

Current position: Discussions are on-going with NU FMS regarding identification and access to relevant policies and protocols etc.

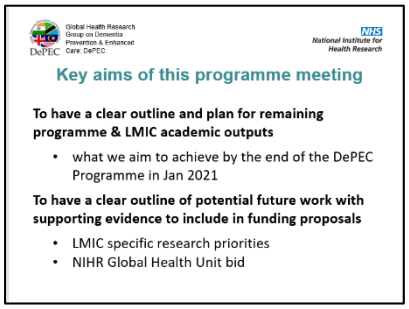
Training Session: Systematic Review: *Prof Michaela Goodson, Dr Susan Hrisos & Emma McLellan*

Systematic Review Training Session wit

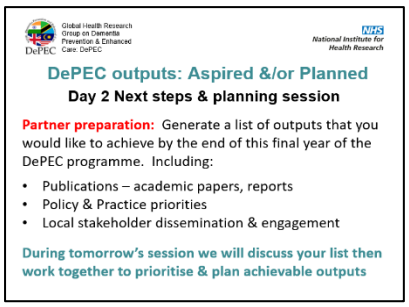
Powerpoint slides with supporting guidance notes attached

It was suggested that a slide or two on inter & intra- reliability statistics for reviewing and application of study criteria to studies etc could be added to this presentation/ training session.

Day 2 PM

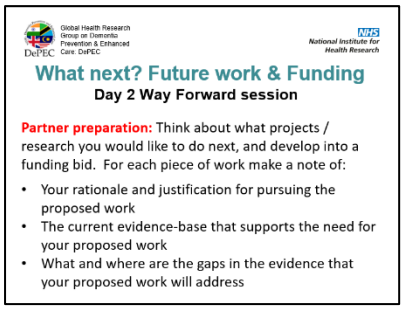


The afternoon of Day 2 was dedicated to planning for a) What we aim to achieve by the end of the DePEC Programme, and b) identify LMIC specific research priorities that could inform the planned NIHR GH Unit bid.



Each partner spent some time discussing and then prioritising potential outputs that they wished to achieve by the end of the DePEC programme.

Outcome: (attached) Final steps for depec All partners 2



Each partner spent some time discussing and then prioritising **LMIC identified research needs and potential projects** that could inform the NIHR GH Unit bid.

Photos