**NIHR Global Health DePEC Group**

**First workshop report – 4-6th September 2017**

**List of Attendees**

Louise Robinson (LR), Director, Newcastle University Institute for Ageing and Professor of Primary Care and Ageing, Newcastle University

Blossom Stephan (BS), Senior Lecturer, Institute for Ageing, Newcastle University

Mario Siervo (MS), Lecturer in Nutrition & Ageing, Newcastle University

Lynne Corner (LC), Director of Engagement, Faculty of Medical Sciences, Newcastle University

Richard Walker (RW), Consultant Physician, Northumbria Healthcare NHS Foundation Trust

Stella Paddick (SP), Training Fellow, Institute of Neuroscience, Newcastle University

Eleni Magklara (EM), Research Associate, Health Psychology, Newcastle University

Catherine Dotchin (CD), Consultant Geriatrician, Northumbria Healthcare NHS Foundation Trust

Matthew Prina (MP), Lecturer in Aging and Mental Health, King’s College London

Jill Manthorpe (JM), Director, Social Care Workforce Research Unit, King’s College London

Michaela Goodson (MG), Dean of Research, Newcastle University Malaysia

Tan Maw Pin (TMP), Associate Professor, University of Malaya

Daniel Reidpath (DR), Professor of Population Health and Head of Public Health at Jeffrey Cheah, School of Medicine and Health Sciences, Monash University Malaysia

Pascale Allotey (PA), Professor of Public Health, Jeffrey Cheah School of Medicine and Health Sciences,

Monash University Malaysia

Devi Mohan (DM), Senior Lecturer in Global Public Health, Monash University Malaysia

Declare Mushi (DM), Lecturer, KCMU College, Tumaini, Tanzania

Thomas Iype (TI), Neurologist, Medical College Trivandrum, India

Rajamohanan Pillai (RP), Department of Paediatrics, Somervell Memorial CSI Medical College and Hospital,

Kerola, India

Ssenku Safic (SS), Clinical Psychology, Shahid Beheshti University of Medical Sciences

**Aims and Objectives of the first workshop**

The timetable for the first programme team workshop is shown in Appendix 1.

**Introduction to Programme**

LR provided a summary of the DePEC programming including the individual workstreams and their subsequent outputs.

WS1 – Establishing the group; dementia care and research mapping for each partner country

WS2 – Development of tools for identifying cognitive impairment and dementia in LMICs

WS3 – Set up a dementia risk reduction research in partner LMICs

WS4 – Determine efficient and feasible dementia care models/care pathways for partner LMICs

WS5 – Develop an impact strategy for partner LMICS and hopefully a bid for a future DePEC Unit

**Programme Outputs**

* Consensus strategies to reduce future dementia risk
* Evidence-based novel approaches to identify those with dementia and those at high risk of future dementia
* Recommendations for efficient and feasible dementia care pathways
* Innovative, practical methods for training the healthcare workforce and supporting family carers

Monitoring and Initial Six Month Review

Key areas will include:-

* Robust governance at both local and national level and establishing an external advisory group
* Efficient programme management
* Robust financial and risk management: Quarterly financial reporting – actual spend and distribution across DAV countries e.g. 15 January, 15 April, 15 July, 15 October
* Due diligence and audit process throughout the programme

Six month review

The team was informed of the NIHR’s post award decision to undertake a formal 6 month review. As WS1 was the key focus of the first 6 months, this was felt to be timely as the team already had an inbuilt “6 month review”. The team agreed key milestones to be achieved in the first 6 months in addition to completion of WS1. These included (DePEC specific milestones listed below each core theme/area):-

* **Build partnerships and collaborations e.g. meetings/visits**
  + 1st whole project team workshop – September 2017
  + Partner country key stakeholder events

Tanzania – 2-4th October 2017

Malaysia – 6-8th November 2017

India – January/February 2018 TBC

* **Understand local context: current care, existing research, workforce capacity and training needs**
  + Partner country “reports” – mapping of dementia care and research
  + Priority setting – workshops; Delphi survey of professionals
  + Patient/public participation strategy for programme
* **Establish robust MoUs, research governance and equitable leadership and decision-making mechanisms**
  + Contracts and MoUs (latter with Malaysia and Tanzania if possible in first 6 months)
* **Obtain pilot data to initiate research**
  + WS1 – identify/prioritise key areas for future research and service development
  + WS2 – screening/diagnostic tools: scoping reviews to identify need for formal systematic reviews to be completed
  + Pilot work - identification of local data sets/projects
* **Communication with key stakeholders – national/local community**
  + Professional/government/organisational links
  + Patient/public participation strategy for each partner LMIC
* **Identify potential partner groups undertaking similar or relevant research**
* **MoUs** – identify if any in place already between partners. Issues with getting the paperwork processed, need to document and show willing but let NIHR know the 6 month timeline is not feasible. If we can say we have existing ones and some in process.

**ACTION: LR/BS/TL/RW**

**Stakeholder Engagement**

This is key to achieving appropriate impact in each country. The team discussed examples of previous

patient/public and professional engagement in each of the partner countries and what works and what

doesn’t.

It is important to acknowledge each country starting from a different point with little/no PPI to date in Tanzania and India.

India and Tanzania did not consider the proposed method of a Delphi survey for seeking professional views as a feasible method for use in their countries. Alternative methods such as focus groups and workshops to be considered.

TANZANIA

a) Professional Stakeholder Engagement – National Events in partner LMICs

This coincides with Mental Health Week in Tanzania. The Minister of Health is attending and this may generate press coverage. RW and SP outlined the plans for the 2 day event including an introduction to the project followed by round table discussions to identify their priorities for dementia care/research. The team have been asked to present lectures on a range of mental illnesses including dementia eg depression in older people. A second workshop is planned for early 2018 with people from all over Tanzania with an interest in mental health. Official permission has been granted from the regional medical officers for representatives from each region to attend the workshop; these are key stakeholders as there is no older person’s mental health provision of any kind in Tanzania.

Expected outputs? – is dementia something you come across in your work? What do you think about it? Getting the local understanding.

The first workshop also follows the ADI launch of a report on dementia in Africa, and a meeting in Nairobi to launch this.

b) Public/Patient Involvement (PPI)

SS has useful experience in this area which can inform our strategy. General informative discussion about innovative options in partner countries including religious, organisations, school leaders, retired “elite” and resident associations, Alzheimer’s International already a partner organisation. For NIHR, the team will need to differentiate between engagement, involvement and participation.

MALAYSIA

a) Professional Stakeholder Engagement:

Event to be held at Monash, Malaysia. DR, PA, MP and MG to discuss potential participants and content; LR to attend and provide programme introduction and expert facilitation. Tanzania to share feedback from their first event with Malaysia and India teams.

b) Public/Patient Involvement (PPI)

Monash Malaysia team have considerable experience of this with SEACO project; discussion of the range of approaches used followed.

INDIA

Professional stakeholder event; first event to be planned for January/February 2018 with LR to attend. India team to draw up potential list of participants. They have limited experience in this area and in PPI and so may require pre-workshop visit from LR to help with planning.

**Partner Country Updates – Mapping of Current Care and Research**

The full reports for each partner country can be found in Appendix 2.

1. **Malaysia**

Key points:

Life expectancies slightly lower in Malaysia than UK by 8/9 years; main cause of death, heart disease.

Population 6% aged 65 years and above.

Prevalence:

Dementia prevalence; accurate prevalence is lacking but estimated 123,000 people aged 60 years and over with dementia.

Policy:

National Policies for Older Persons (1996) revised 2011 and National Health Policy for Older Persons 2008; no specific dementia care policy.

Dementia care:

Clinical care guidelines: developed in 2008 and require revision but no-one interested in doing it; guidelines include algorithm for anti-psychotic use and psychosocial interventions.

Care provision: government, NGOs, family care, family have ability to access the memory clinic services direct.

Private nursing care at home for 24 hour care if family can afford it. Institutional care – number of beds going up but registration process is complicated.

NGOs provide a lot of residential care for older people, but not free (~ 300 MYR per month). Have a lot of donations so not underfunded but under managed. Also provide care giver support. Very few social workers in Malaysia. Home help services come in twice a month. Free hospital transportation organised by local councils, funded by the welfare services. Expectation that a member of the family stay in hospital with the patient to provide the basic care. If you have money you will pay a care giver, hire a private nurse.

Difficult to use a diagnostic tool due to different language speaking groups and ethnic groups. Usually very severe before they present (behavioural problems). Care givers often come to memory service as proxy as participants can’t attend due to disability.

Number of geriatricians increased considerably. Issues with training psycho-geriatricians so former speciality more usually involved. Government sent a geriatrician to Japan to look at Kumamoto Model pilot (Klang).

Dementia Education – unsure how many of the medical courses offer a geriatric curriculum, let alone specific teaching on dementia. Not enough house jobs as producing 7000 doctors per year for 1000 house jobs.

Research to date:

Studies have been subjective and poor quality. Not much about care givers.

Lack of accurate prevalence rates, quality of care - geographical inequalities with east coast a poor distribution of services, question about amount of education, need for a good cognitive diagnostic/screening tool, social care provision, quality of research is poor - this provides an opportunity to raise the game about it.

**Challenges identified by DePEC group**

Healthcare – accurate diagnosis; care provision

Accurate and feasible cognitive assessment tools

Implementation of good practice on large scale (significant rural areas)

Social care provision

Multi-ethnic communities

Workforce issues

ii. **Tanzania**

Older people generally live with extended family. High level of illiteracy. Little migration, stable population.

Prevalence:

Dementia study in 2010 in people aged 70 or over, using census data (have samples to look at APOE when have funding, samples are in Newcastle). Little data on risk factors but most people with HIV live in sub-saharan Africa; dementia is a well-known complication living with HIV.

Dementia awareness is limited – no Swahili for the term Dementia or for Carer Burden. 50% of population have no idea of dementia – causes/prevention/treatment.

Cultural explanation– social cultural model is common eg person is possessed by demons, bewitched.

Potential physical, psychological strain and economic challenges – patients are poor, carers are poor.

Dementia care:

Inadequate health services – no dementia specialists and only 4 neurologists in Tanzania.

Caregivers are spouses, daughters, in-laws, house maids. Caregiver has poor knowledge or caring skills.

Patient needs to be able to communicate with carer but most house maids are not from the region.

Found that caregivers practice pluralistic health seeking behaviour – traditional healers, religious prayers and modern care – don’t get proper care or treatment.

Major challenges:

Direct personal care, financial support, conflict among in-laws, reported health effects – feeling lonely, angry, need training in how to care for people with dementia.

Urgent need for awareness raising, training on how to care for PWD, how to deal/cope with challenges, national policies, strengthened health care system.

Policy:

No government strategy or policy at the moment. Advocating for strategy and policy is going through department of non-communicable disease, regional and district medical and mental health officers.

Between 2015-2016 under IDEA project, ministry of health sent district and mental health officers to Moshi to attend dementia training workshops. They are now the ambassadors in dementia policy advocacy.

Communicated via radio shows – 1 hour to talk about dementia, and take questions. Covered parts of Tanzania, over the border into Kenya, Mozambique, Uganda, Rwanda, Malawi, Zanzibar, etc.

Research:

The Idea Study (Identification, and interventions for Dementia in Elderly Africans) – 3 year study. Little research, if any on care or carers.

Developed IADL for rural areas in Tanzania as possible assessment tool.

**Challenges identified by DePEC group**

1. Workforce – task shifted care to non-specialist; lack of specialist care; very little teaching of psychiatry

2. Public awareness – dementia as a medical illness compared to current illness beliefs

3. Post diagnostic care options

4. Diagnostic assessment tools

**ACTION: Richard to email Pascal for introduction to in-**

**depth network**

**Ssenku to send list of questions people asking on radio**

**Possible ideas**

* **Dementia as a disability rather than a disease? Links into the assessment tools looking at ADL and the environment.**
* **Work specifically done with carers, talk about bringing together the evidence we have or do a scoping review across the sites. Role of women in care giver roles in dementia, carer more broadly.**

iii. **India**

7% of population over 60 in India; in Kerala this is 14%.

Prevalence:

Very few incidence studies in India, most studies end of 1990s-early 2000s. Top 10 causes of death, Dementia is 7th position.

Policy:

National Mental Health Policy but no dementia specific policy.

Dementia care

Diagnosis is clinical and a single primary diagnosis needs to be documented in every case.

Reporting of death is mandatory but no systematic disease scope; cause of death reported as miscellaneous brain causes – 3.2%. Now being changed to use of term dementia.

Death certification – who writes the certificate?

A doctor. If a patient dies at home it is reported to the local authority. They will send a health inspector, not a doctor, Inspector asks about previous health issues. Health inspector has a paramedic qualification. 99% of deaths happen in hospital in Kerala. If die in the care home, they take the body to the hospital for clarification. Don’t always get a death certificate, compulsory to register the death but not to have a certification. For some legal reasons you need a death certificate eg transfer of pension rights etc.

In Africa, they currently use a verbal autopsy protocol. In Malaysia, from this year, they are introducing verbal autopsy protocol for any deaths not occurring in hospital.

Screening tools used MMSE but may need adaptation. Kerala State Mental Health Authority constituted by the government in 1993.

District Mental Health Programme is the flagship of the Government of India. Now in 225 districts in the country.

Care giving is given through the health systems, primary health network and family.

Treatment recommendations – no specific care guidelines in India.

Dementia specific facilities – only a handful of full time dementia care centres. Two day-care centres in Kerala and urgent need to increase.

The norm is nuclear family and women have taken up work. In Indian culture, institutionalisation is not accepted although this may be changing. Informal care is given. Everyone is known to everyone and they take care of each other.

Education and training – concentrating on tools in the local language. Indian council of medical research is fostering education and training, Indian academy of Neurology (IAN) – cognitive subsection.

Research:

Research into diagnosis – peaked during 1990s with 10/66 study (Martin Prince, KCL).

Cost of studies - lack of cost effectiveness information. Some studies on key risk factors for dementia.

Review of epidemiological research in India – quantify the burden is important challenge.

Current study – psychiatric morbidity in the community. Estimated prevalence was 10.4%

Intervention studies are almost non-existent. Care centred around primary health care model.

**Challenges identified by DePEC group**

1. Workforce: knowledge and attitudes of doctors (especially UG medical training)

2. Cognitive assessment tools and training of assessors

3. Roles of other health care professionals e.g. nurses and pharmacists

4. Accurate prevalence

5. Dementia as Public health issue despite well-established public health network

iv. **England**

Prevalence:

Risk of developing dementia – 1 in 14 over 65s, 1 in 6 over 80s.

Diagnostic rates have increased considerably in the last 10 years following policy recommendations.

Heart disease still the leading cause of death for men but dementia leading cause of death for older women; more accurate reporting on death certificates since 2009 using dementia and sub-terms.

Policy:

National audit office reports, 2007 released one on dementia; 2011 first Prime Minister’s challenge on dementia, with the second in 2015 with prevention and risk reduction being key.

Shift towards a public health approach not just a clinical issue.

FINGER trial – randomised controlled trial, complex lifestyle intervention – early findings controls 31% greater risk of cognitive decline.

Dementia care:

Clinical care pathways and evidence based guidance; latter being updated with new NICE guidance hopefully published by summer 2018.

These will also include research recommendations for the UK showing where the gaps are.

Currently GPs not allowed to make a diagnosis, must be made by a specialist.

Prescribing started by secondary care physician but continuation of dementia drugs by GP.

Social care and support – private providers offering care homes and care services, day services, carer support. This provision varies around the country.

Technology – lots of devices and technologies available. Knowledge in health care professionals is very low and discussion very rarely arise in clinical consultations.

Education and training – GPs and medical students receive little training compared to the size of the problem. Not currently training doctors to meet the needs of an ageing population.

Carer support:

Dementia MOOC produced by Newcastle University and taken up by 102 different countries (20,000 carers).

Greater emphasis on institutional care – UK could learn from other country’s best practice for family support.

There are specific standards for care homes to meet criteria of dementia care home.

Research:

Quantity and quality of research increased considerably in last decade. Focus largely on cause and cure, less on quality of care. National Dementia Institute announced in 2017; £150M but largely on biomedical care. Increasing shift towards care and prevention, led by Alzheimer’s Society.

**Available data and resources**

a) SEACO Study - South East Asia Community Observatory

PA provided an introduction to the SEACO study (see Appendix) and collaboration to date. Pilot work already instigated between Newcastle University and Monash Malaysia.

Strong stakeholder involvement with community engagement committees every 3 months. Creative in different ways of communicating and engaging with public and patients.

Core team within field staff. Full time data collectors; data collected on tablets (Everything open source).

Very good primary care system but little follow up when in secondary care.

Had to innovate quite a bit, looked at use of screening tools, gait analysis (space in homes not always long enough); feasibility studies – what works and what doesn’t work.

Have a group of private practitioners who are ‘friends’ of SEACO. They will see high risk patients free of charge for the first consultation.

Assessments to date 4m gait speed; MMSE for CI; hand grip strength, ECG screening.

Falls data – retrospective – have you suffered one fall in the last 6 months, and how many falls in the last 6 months?

Most of the people living in extended families but between ages of 19-24 there is a gap. Live/work away, go home for holidays.

Institutional care facilities? Zero. There is primary care clinics, hospital and community clubs.

b) University of Malaysia

Frailty data collected but not analysed.

**ACTION: TMP to investigate and share with full team**

c) India

No data mechanisms for dementia research, especially for prevalence.

Census of India collected every 10 years. National mental health survey in 2015-16 – sample survey, not a census.

Latest census has included information on ageing and disability.

Prolife cohort – published 2009. J Int Epid.

Deaths medically certified, as mostly urban area. If remote, then verbal autopsy done.

d) Tanzania

Number of studies over the years. Undertaken by RW and his team. Would like to do a nutrition follow up. Low BMI an issue. Issue of anaemia a problem. Reliant on hospital blood sampling. In patient study, given B vitamins, improvement in Parkinson’s study.

Finance and Governance

A very useful meeting was held with the Finance and Contracts team (see Appendix 3).

**ACTIONS**

* **Need list of equivalent financial contracts in partner (TL) LMICs**
* **MOUs to be investigated between Newcastle and partner LMICs (LR, RW, TL)**

**Appendix 1**

**DAY 1: Monday 4 September 2017**

**Location: Newcastle University, Room 2.25 The Core (see below for directions)**

**Start Time: 9:00am**

|  |  |  |
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| **Time** | **Allocation** | **Description** |
| 09:00-09:20 | 20 mins | **Welcome and introductions**  [*Professor Louise Robinson*](01%20Robinson_Louise%20Introduction%20DePEC%20Programme%20overview.pptx) |
| 09:20-09:50 | 30 mins | **Director Opening – Summary of program and six month review requirements**  [*Professor Robinson*](DePEC%20Programme%20overview.pptx) |
| 09:50-10:15 | 25 mins | **Morning tea** |
| 10:15-11:15 | 1 hour | **Update on research and dementia care in Malaysia**  [*Professor Goodson and Dr Tan*](02%20Tan%20and%20Goodson%20Dementia%20in%20Malaysia.pptx) |
| 11:15-12:15 | 1 hr | **Update on research and dementia care in Tanzania**  [*Ssenku Safic*](03%20Safic%20Dementia%20research%20in%20Tanzania.pptx) |
| 12:15-13:00 | 45 mins | **Lunch** |
| 13:00-14:00 | 1 hr | **Update on research and dementia care in India**  [*Professor Iype*](04%20Iype%20Dementia%20research%20in%20India.pptx) *and* [*Dr Rajamohanan*](04%20Rajamohanan%20Dementia%20research%20in%20India.pptx) |
| 14:00-15:00 | 1 hr | **Update on research and dementia care in UK**  [*Professor Robinson*](05%20Robinson%20Dementia%20research%20in%20UK.pptx) |
| 15:00-15:30 | 30 mins | **Afternoon Tea** |
| 15:30-16:30 | 1 hr | **Group discussion: WS1 discussions including update on research gaps and priorities**  [*Professor Louise Robinson*](DePEC%20WS%201%20UK%20dementia.pptx) |
| 16:30-17:00 | 30 mins | **Summary**  *Professor Louise Robinson* |
| Break |  |  |
| 18:30 | - | **Dinner**  Blackfriars (<http://www.blackfriarsrestaurant.co.uk/>). Directions attached below |

**DAY 2: Tuesday 5 September 2017**

**Location: Newcastle University, Room 2.25 The Core (see below for directions)**

**Start Time: 9:30am**

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| **Time** | **Allocation** | **Description** |
| 09:30-09:45 | 15 mins | **Coffee** |
| 09:45-10:30 | 45 mins | **Newcastle University Joint Research Office – Finance and Contracts (including time for questions)**  *Fiona Airey and Matthew Stewart* |
| 10:30-10:55 | 25 mins | **Morning tea** |
| 10:55-12:55 | 2 hours | **WS2 Discussions (4 \* 30 minute presentations)**  1. Dementia risk prediction models [*Dr Stephan*](06%20Stephan%20NIHR_Risk%20Prediction%20WS2.1_V1.pptx)  2. Dementia risk model development: The 10/66 dataset [*Dr Prina*](07%20Prina%2010_66%20study.pptx)  3. Dementia diagnosis tool development [*Dr Paddick*](03%20Paddick_Dementia%20research%20in%20Tanzania.pptx)  4. Update on scoping reviews [*Dr Magklara*](DePEC%20Slide_Eleni.pptx) |
| 12:55-13:40 | 45 mins | **Lunch** |
| 13:40-15:40 | 2 hours | **Data resources and translation of research into practice (Presentations and discussion) including:**  1. SEACO Study*Professor Allotey*  2. Other Malaysia Resources *Dr Tan*  3. Data resources in India  4. Data resources in Tanzania *Professor Walker* |
| 15:40-16:00 | 20 mins | **Afternoon Tea** |
| 16:00-16:30 | 30 mins | **WS4 Work plan and work allocation**  *Professor Robinson* |
| 16:30-17:00 | 30 mins | **Future workshop planning**  *Professor Robinson* |

**DAY 3: Wednesday 6 September 2017**

**Location: Newcastle University, Room 2.25 The Core (see below for directions)**

**Start Time: 9:30am**

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| **Time** | **Allocation** | **Description** |
| 09:30-11:00 | 1.5 hours | **Roundtable discussion – WS1, 2 AND 4**  *Professor Robinson* |
| 11:00-11:15 | 15 mins | **Morning tea** |
| 11:15-12:45 | 1.5 hours | **Small workgroup discussions focused on WS1, 2 AND 4**  *Overseen by WS leads* |
| 12:45-13:30 | 45 mins | **Lunch and meeting close** |