NIHR Global Health DePEC Group

Workshop report Malaysia – 7-9th November 2017

List of Attendees

Appendix 1 lists the attendees at the Malaysian DePEC workshop held at the United Nations University, Kuala Lumpur.

The invited stakeholders included representatives from the following groups:

- Clinical academics involved in Geriatric and Psychogeriatric care from Public Universities in Malaysia,
- Ministry of Health, Malaysia who provide care in the primary and secondary care setting.
- Ministry of Women, Family and Community Development
- NGO Alzheimer's Foundation Malaysia
- Senior citizens Association
- United Nations
- Epidemiologists
- Health Economists
- Malaysian Institute of Ageing
- Psychologist
- Preventive Medicine Specialists
- NGO- UNFPA (United Nations Development Fund)

Aims and Objectives of the first workshop

The aims of the first workshop were:

- 1. To bring together stakeholders involved in Dementia care to ensure and provide a summary of Ageing and Dementia Care research in Malaysia to date.
- Create a forum for stakeholders involved in Dementia care to have an opportunity to collectively discuss and identify research priorities and challenges for Dementia care in Malaysia
- 3. To create a network through which stakeholders could be involved in developing projects related to research priority areas.
- 4. To introduce the DePEC study in Malaysia and outline pathways for future research and development of the Malaysia network into the basis for a hub of Dementia research in LMICS of South East Asia

In order to achieve the aforementioned aims, a workshop was organised involving invited stakeholders to come to a consensus agreement on priorities for research on Dementia care in Malaysia and negotiating challenges to its delivery.

Introduction to Programme

In the third presentation (Appendix 4) stakeholders were introduced to DePEC and the various workstreams involved over a 36 month period for Malaysia. In addition, an explanation of the parallel work being undertaken in Tanzania and India was given to ensure stakeholders could see how their input was contributing to Global knowledge on Dementia care and challenges faced in other LMICS. The workstreams for the overall DePEC study were explained as follows:

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

Following this introduction, stakeholders were invited to participate in a large group open Discussion to identify what they perceived to be the challenges for delivery of Dementia Care In Malaysia and future research priorities.

In the afternoon session, small groups of stakeholders were invited to address in groups of 5 or more, one of the 5 priority areas that the larger group had identified and think about what the barriers were to either undertaking research in that area or delivering care and thinking about strategies to address the challenges.

At the end of the session, a representative from each of the 5 groups presented the group's strategies and list of challenges to all the workshop participants and questions on the topics were subsequently

Invited.

Workshop Programme Outputs

- Consensus strategies on research priorities and challenges in Malaysia
- Development of a Dementia care research network including Patient and Public Involvement for Malaysia
- Consent for publishing the consensus of the DePEC workshop

Summary of workshop outcomes- Session 1: Large Group Discussion

All stakeholders were individually invited to present to the wider group, their views on what they perceived as the challenges to dementia care in Malaysia and the priorities for research and enhancing existing care.

Patient and public involvement (PPI)

Patients, Alzheimer's Foundation and carers felt that there was a need to improve information for dementia patients and carers on access to dementia care including, prevention strategies, diagnosis, prognosis, treatments, access to respite care, support for caring including formal paid carers and informal unpaid carers (voluntary organisations, friends and family) and access to "regulated "specialist care facilities.

Stakeholders in General

The following were identified as challenges in Malaysia:

- 1. Regulation and governance of service providers including nursing homes, residential homes and day care facilities
- 2. Policies and funding for caring for patients with dementia in general as many are out of date from 1990s
- 3. Appropriate models for dementia care in middle income countries as the current model relies heavily on filial piety which is not sustainable given that many young people now wish to live overseas
- 4. Diagnostic tool validation in the various languages and spoken dialects in Malaysia
- 5. Accurate epidemiology statistics (may are based on rural settings where recording numbers is easier than in urban settings)
- 6. Limitations of Cochrane reviews and Dementia care guidelines from Western countries where the evidence base and cost effectiveness of recommendations may be irrelevant for Malaysia.
- 7. Lack of research in general on evidence base for various ethnic groups in Malaysia
- 8. Specialty training was identified as an issue both for doctors and allied health professionals. There are specific training pathways for some doctors, but there is a lack of training for other health professionals and carers so governance on the quality of care and regulating individual practitioners isn't currently possible.
- 9. Recruitment of carers- caring is not seen as a popular occupation and as such is provided mainly through family members and NGOs. There are no certificates or diplomas to qualify for such a role and in many cases no training.

Following identification of the above challenges, the group as whole prioritised the following issues for improving Dementia care in Malaysia and these became the topics for small group discussion in Session 2

- 1. Prevention and Screening
- 2. Human Resource and Training
- 3. Awareness and Health Literacy
- 4. Integrated care and regulation/governance of care
- 5. Government Strategy and the Policy Journey

Summary of workshop outcomes- Session 2: Small Group Discussions

All stakeholders including members of the public were invited to join one of the aforementioned groups for further discussion. The questions that the groups had to answer were as follows:

- 1. What needs to be addressed?
- 2. Who is needed to "make it happen" (stakeholders)?
- 3. What is your strategy?

The outcomes of the small group discussions were presented to the wider group and are as follows:

Group 1: Prevention and Screening

1. What needs addressing?

- Standardised tool (s) for screening that is used nationally and validated for different ethnic and population groups. Challenges include the differences in literacy for some older patients making some tools difficult to use.
- Training for health care providers in using the tools is also required along with a standard protocol for administration of the tools
- A registry of Dementia patients would also be helpful both for research and clinical follow up as it is difficult to know how useful these tools are over time given that patients may access any number of health care professionals throughout their lifetime unlike in the UK where patients will tend to go to the same general practitioner or practice as a matter of routine.
- Medical Officers are not always trained in use of screening tools and care of Dementia patients. Many of these officers will move from post to post and given the small number of Hospital Specialists in Malaysia (n=13) caring for Dementia patients, these medical officers are often the first and only point of care

2. Who is needed to "make it happen" (stakeholders)?

- Ministry of Health and Malaysian Medical Council- to regulate reporting to a Dementia Registry and standardising use of guidelines and specific validated tools.
- Ministry of Higher Education- to facilitate higher training for secondary and tertiary care in use of tools and prevention strategies
- NGOs- to inform patients that specific tools need to be used over time to monitor management
- Senior Citizens associations- to ensure patients and carers understand why specific validated tools are important
- Private organisations delivering care- many patients may go direct to private care settings and will be lost to follow up and registration if Private care facilities are not engaged in the registry process.

3. What is your strategy?

- Awareness & screening campaigns- led through Alzheimer's foundation for example of NGOs, to help remove the stigma attached to dementia and address Dementia as a preventable condition in the process of Ageing.
- There was an identified need to focus on rural & urban communities differently to ensure engagement in the process as filial piety and family care is much more prevalent in rural communities and intervention may be seen as threatening.
- Build a body of evidence through research using Malaysian patients to look at preventive strategies and lifestyle modifications that could help with public awareness also as patients may not see studies undertaken in Western Countries as relevant to them.

Group 2.Human Resource and Training

- 1. What needs addressing?
- There is a perceived lack of exposure and training in Dementia Care at all levels both in Medicine and Society in General.
- Recruiting formal paid carers in particular is difficult because it is not seen as a lucrative or "valuable" profession. Carers often come from other LMICs with or without any training and are often employed as household "maids" but take on caring roles with senior members of the family. These carers are often from Philippines or Indonesia and as such may have language or cultural difficulties with the patients and carers they are working for.
- The feeling from Senior Citizens is that they would prefer to be cared for by someone from the same ethnic/cultural/religious background as themselves and ideally speaking the same language which is often not the case.
- In medicine, medical students get very little in the way of exposure to patients with
 Dementia and dementia care because they have a very specific set of learning outcomes to
 fulfil MBBS which are not largely met using Dementia patients and the Dementia care
 models. "There are easier patient groups to work with to meet these learning outcomes
 more effectively and efficiently".
- Training of Medical Officers is underfunded. Recruiting specialists through the Malaysian Specialist Training programme is difficult both from a funding point of view and lack of existing trainers to train the next generation.
- The specialty is not a popular choice because of lack of perceived private practice and career progression. There are many more lucrative career opportunities in Medicine than geriatric care or geriatric psychiatry.

2. Who is needed to "make it happen" (stakeholders)?

- Malaysian Medical Council
- Malaysian Medical Schools
- Ministry of Health
- Ministry of Higher Education/Education;
- Immigration and overseas work visa awarding agencies

3. What is your strategy?

Malaysian Medical Council and Malaysian Medical Schools:

This would ensure Dementia care receives sufficient input into the undergraduate curricula. Private Medical Schools would also have to negotiate sufficient time in their programme delivery to ensure they are meeting the needs of the Malaysian population healthcare as well as the countries from which their programmes are primarily designed for (UK, Australia, and Canada)

Malaysian Medical Council and MOH

Malaysian Medical Council and Ministry of Health need to work together on Specialty training and should perhaps consider more community led services to ensure that the work pattern in secondary care doesn't become too monotonous and pressured. Dementia patients are usually placed in general medical wards and the demands of acute medical patients mean that Medical Officers have insufficient time to spend with Dementia patients and train specifically to look after them.

Malaysian Medical Council and Ministry of Higher Education/Education;

Involvement of these agencies would help to regulate quality of care from formal and informal carers if a qualification at certificate or diploma level and subsequent regulation/licensing with a professional body was to follow.

Group 3. Awareness and Health Literacy

1. What needs addressing?

- Awareness of Ageing and Dementia care in general and related problems is poor in the General Population
- There are many aspects of ageing including co morbidity, incontinence, memory loss that evolve in the same individual for which there is no information that is easily accessible
- People do not like pamphlets and many older people may be unable to read
- Not all people have WI-FI connection and access to internet resources
- Television campaigns may be useful but are non existent at present.
- There are no telephone helplines or on line resources in Malaysia from where information can be obtained that is up to date and regularly updated.
- Patients or carers need to live near a care centre to get information which are almost all in Kuala Lumpur so this doesn't serve the rest of the population who live elsewhere in Malaysia
- Prevention campaigns are important because people will only log on to Dementia websites
 once they have already identified dementia. It is not addressing the preventive needs of the
 ageing and well population.
- "General public and police need awareness also as social media has become a means of finding lost dementia patients and the police need to be sympathetic to the needs of dementia patients when they find them"
- There needs to be information on the addressing the stigma of dementia, denial of dementia and psychological aspects as well as where to locate care facilities, experts and NGOs and treatment options.

2. Who is needed to "make it happen" (stakeholders)?

- Policy makers
- General public
- Healthcare practitioners
- Traders/business sector
- Policemen
- Public transport
- Malaysian Social Media sites e.g. What's ap groups/Facebook to help look for lost dementia patients

3. What is your strategy?

- Awareness and health literacy starts with education/training from school age children upwards
- Education and training should start from young and young adults/teenagers should be encouraged to volunteer as carers with it giving some credit e.g. for University entrance
- National Education Curriculum on Ageing
- Via media/information on TV.
- Social media, IT.
- Incentivise/pay carers from government funds as they will be the best advocates for future training and awareness campaigns.

Group 4: Integrated Care_Regulation_Governance & Quality

1. What needs addressing?

- What is available in Malaysia? There are services available in primary, secondary, tertiary healthcare and institute of gerontology but all are working in silos. There is lack of coordination and communication and the interface of the hospitals and ministry and primary care needs to work more smoothly.
- Policy, guidelines and action plans need to be updated and integrated from the primary, secondary and back to primary care interface.

2 Who is needed to make it happen? (Stakeholders)?

- MOH family division (elderly Sektor Warga Emas),
- NCD, development division
- Ministry of Women, Family & Community Development
- Local government in state/district/council
- Malaysian Medical Council
- In rural areas, the leaders of the Mosque or Village Penghulu will need to be involved in integrated care pathways as there is still tendency for people to practice traditional medicine which is often not evidence based in comparison to conventional medical care because it is more convenient and often has religious affiliation.

3. What is your strategy?

- Training staff, nursing home/care provider, paramedics, and doctors. A Training module is available from primary healthcare providers for doctors, staff, nurses, community nurses, but it needs updating and there needs to be more educational material to make it worthwhile and fit for purpose.
- Multidisciplinary team working: Collaborating between departments in the hospital through and specialists. This happens in some places, but not in all as there are insufficient numbers of specialists and allied health care professionals working in these areas

- Pathways in primary and secondary care are indistinct and difficult to negotiate when
 moving form one area to another. There needs to be Nationalised Pathways of care that
 function in a similar way in every state from the first referral from primary care through the
 entirety of management.
- There needs to be more community management of Dementia and support for carers in the community as family members are currently required to give up work to look after aged parents and relatives. Home help services are available in some areas, but are not widespread and so an integrated care pathway will need to engage with all these types of services also if an integrated care pathway is to become a reality.
- The "Aged Care Act" has apparently been discussed in Parliament recently (within the last few weeks) but the details are not publicly available and cannot therefore be discussed presently.

Group 5: Strategy Policy Journey

1. What needs addressing?

- The discussion was based on available and related existing policies in Malaysia.
- Is a new policy required or are existing ones updated and integrated?
- It is important to address healthy ageing rather than just dementia per se

Who is needed to make it happen (stakeholders)?

- Ministry of Women, Family & Community Development covers welfare of the elderly
- Ministry of Health covers health issues
- Ministry of Housing- Local Government covers housing issues for elderly
- Economic Planning Unit EPU
- Ministry of Human Resource
- MOSTI
- R&D collaborations
- Ministry of Higher Education

• Challenge: Economic burden of dementia in Malaysia presented idea/concept to Ministry of Finance, but they wanted to know what would be the return in investment? How much would be the saving on acute health care and other costs be?

3. What is your strategy?

- First step is the need to convince the stakeholders on the urgency of ageing issue as well as Dementia.
- Take other countries for example as benchmarks then review existing policies and decide the best approach for Malaysia. An example would be Japan, but they are not LMIC.
- Exchange training programmes for health professionals
- Invite Japanese companies to set up care organisations in Malaysia
- Work out a model and cost savings in terms of health economics to ensure that the Government is able to support initiatives to change policy and deliver care in a more integrated way.

Summary of outputs

- On completion of the workshop, all members consented to publishing the outcomes of the meeting as the first step in improving Dementia care in Malaysia
- A network of Stakeholders and policy makers has been formed from the workshop who will
 communicate primarily electronically, but will meet formally when new research project
 collaborations are set up to facilitate delivery of the workstreams.
- A closed social media site is being developed to enhance communication within the stakeholder group and raise awareness of research and initiatives to enhance Dementia care in Malaysia.



Networking event NIHR Dementia Global Health Programme (DePEC)

Date: 7 November 2017, 9.00am - 5.00pm

Venue: UNU-IIGH, UKM Medical Centre,

Jalan Yaacob Latif, Bandar Tun Razak, Cheras 56000, Kuala Lumpur.

Website: www.iigh.unu.edu | Contact: 03-91715394 | Email: iigh-training@unu.edu

Registration

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Networking event

NIHR Dementia Global Health Programme (DePEC)

United Nations University-International Institute of Global Health (UNU-IIGH)
UKM Medical Centre, Jalan Yaacob Latif, Bandar Tun Razak, Cheras

7th November, 2017

0.00.0.20	/" November, 2017
9.00-9.30	Registration
9.30-9.45	Welcome address
	Prof Pascale A Allotey, Director , United Nations University-International Institute of
	Global Health
0.45 0.55	Presentation: Ageing and Dementia- Current scenario in Malaysia
9.45- 9.55	1. Ageing in Malaysia
	Dr Devi Mohan, Senior lecturer in Global Public Health, Jeffrey Cheah School of
0.55 10.15	Medicine and Health Sciences, Monash University Malaysia
9.55- 10.15	2. Dementia and dementia research in Malaysia
	Dr Tan Maw Pin, Associate Professor, Department of Medicine, University of Malaya
10.15 - 10.45	Presentation: Introduction to NIHR DePEC programme
	Dr Michaela Goodson, Dean of Research, Newcastle University Medicine Malaysia
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10.45- 11.15	Coffee break
11.15- 12.15	Open discussion
	Interactive sessions on:
	 Identifying the challenges for dementia and geriatric research in Malaysia
	 Research priorities for dementia in Malaysia
12.15 - 12.30	mydumbbell™: Pillow Dumbbell Exercise
	Dr Lee Yi Yi, Research Officer, UNU-IIGH
	Grouping exercise
12.30- 13.30	Lunch
13.30- 15.00	Breakout sessions
	Group activities based on the research and intervention priorities identified
	 Identify the key stakeholders in various research and policy domains
15.00- 15.45	Presentations : Summary of group activities
15.45- 16.15	Coffee and networking
16.15- 16.30	Concluding remarks
	Prof Daniel Reidpath, Professor of Population Health and Director, South East Asia
	Community Observatory , Jeffrey Cheah School of Medicine and Health Sciences ,
	Monash University Malaysia

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