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# UK-Korea Initiative:

Optimizing the Impacts of  
National Dementia Strategies

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# OPTIMIZING THE IMPACTS OF NATIONAL DEMENTIA STRATEGIES UK- KOREA WORKSHOPS

## WELCOME AND INTRODUCTIONS

### WELCOME LETTER FROM PROF ALISTAIR BURNS CBE, NATIONAL CLINICAL DIRECTOR FOR DEMENTIA, NHS ENGLAND

*Dear Colleagues*

*I am sorry not to be able to be with you today to welcome you to this exciting meeting hosted by my friend and colleague Professor Sube Banerjee.*

*Dementia is a worldwide challenge and if we are to improve the lived experience of dementia for people with the condition and their carers we need to work together to find innovative solutions.*

*We have made a number of strides in the NHS in England over the last few years in terms of dementia care starting with the National Dementia Strategy in 2009 (co-created by your host today Sube Banerjee) and then energised by two Prime Ministers Challenges on dementia in 2012 and 2015.*

*We have achieved successes in a number of areas. For example, based on the landmark report on the use of antipsychotics in dementia in 2009 we have successfully reduced their prescription by half.*

*We have created a series of Dementia Action Alliances across the country and have created one million dementia friends.*

*In the last few months we have seen the number of people who have a formal diagnosis of dementia in England rise from a figure that was just over one third five years ago to two thirds this is essential for people who need to access post diagnostic support.*

*In England we have looked at developing a pathway for people with dementia based on the title of the National Dementia Strategy and we feel there are five key things that we could do:*

- 1. Preventing well*
- 2. Diagnosis well*
- 3. Living well*
- 4. Supporting well*
- 5. Dying well*

*I know my colleague Kevin Mullins who is there today will be able to describe this in detail.*

*With best wishes,*

*Alistair*



**Prof Alistair Burns, National  
Clinical Director for Dementia,  
NHS England**

## P1. NATIONAL DEMENTIA POLICY IN ENGLAND - RESPONDING TO THE PRIME MINISTER'S CHALLENGE

KEVIN MULLINS, HEAD OF MENTAL HEALTH, NHS ENGLAND

### P1. PRESENTATION SUMMARY

NHS England leads the National Health Service (NHS) in England. It sets the priorities and direction of the NHS and encourages and informs the national debate to improve health and care. Its aim is for people to have greater control of their health and their wellbeing, and to be supported to live longer, healthier lives by high quality health and care services that are compassionate, inclusive and constantly-improving. Following on from the development of the National Dementia Strategy and the formulation of Prime Minister's Dementia Challenge, NHS England has developed policy and quality improvement programmes across dementia prevention, assessment, treatment and care.

One major element of this is the commitment to increase dementia diagnosis rates, with the aim to raise national diagnosis from a third in 2009 to two thirds of people. This target was met and exceeded in November 2015. However this is the national picture, and there is still variation in diagnosis rates across regions due to differences in "ambition" amongst the 209 Clinical Commissioning Groups (CCGs), who are responsible for providing healthcare in their area. The work of NHS England will now be to help all CCGs meet or exceed this target.

Diagnosis is only a one element of a good healthcare system for people with dementia. There is also a need for post-diagnostic support, changing people's attitudes toward dementia and allowing people to die with dignity. NICE guidelines (2010 and 2013) provide best evidence-based standards. At present, dementia services in the UK do not reach these standards. We need to understand better these gaps, produce additional guidelines, and measure how this is achieved.

NHS England is working to aid this progression. The *Well Pathway for Dementia* aims to provide guidance for better diagnosis, care and support for people with dementia and their carers:

- **Preventing well** – Decrease the incidence of dementia by reducing risk factors and behaviours for dementia. One way this may be achieved is through the development of a health check tool.
- **Diagnosing well** – Consistency of diagnosis across different areas. Targets of recruiting half of people diagnosed with dementia into research will make dementia research comparable to cancer and is of value to both research and the people it affects.

- **Supporting well** – Support people with dementia and their carers through early support post-diagnosis and the creating personalised care plans for everyone. Care plans should be meaningful and person-centred. There is a greater need for people to understand dementia.
- **Living well** – Creating dementia-friendly communities based on the needs of people with dementia where those in the community have enough knowledge to accommodate them. Appropriate support within dementia friendly hospital settings with integrated and coordinated care.
- **Dying well** – Every person is entitled to an advanced care plan. Existing guidelines in other areas should be applied to dementia end of life care

## P1. DISCUSSION SUMMARY

**How is the NHS increasing dementia diagnosis rates?** Some doctors were reluctant to diagnose in the absence of treatment, support and care plans. Incentivising primary care and acute services is a method to increase diagnosis rates that has been implemented within the UK. Workshops for healthcare staff to better educate the benefits of an early diagnosis has also been implemented. Quantity is a marker of achievement, there is however a gap in achieving quality diagnosis. Providing empirical evidence that early diagnosis is good, will encourage further diagnosis. We need to communicate this message.

**It maybe that the incentives may result in over diagnosis, what is your opinion?** It is not believed that these incentives are resulting in over diagnosis. Doctors work within ethical guidelines and should not be making false diagnoses. It is also worth noting that diagnosis rates were so low to begin with that false positives are unlikely.

**What are the dementia care costs in the UK?** By accessing fingertips ([fingertips.phe.org.uk/profile-group/mental-health/profile/dementia](https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia)) you are able to observe and compare indices of different elements of dementia care. It is important to understand that many efficiencies result in long term rather than immediate savings.

**What is the UK funding model of dementia services?** Healthcare is tax funded and therefore everyone is entitled to access healthcare services without additional charge. Social care is funded by local councils, so the cost of the service to the user is “means tested”. Therefore anyone that has assets (e.g. a home owner) will have to fund social care themselves. Integration of health and social care is very difficult not only in the UK but across much of the developed world.

**Are there any systems in place within the UK that integrate health and social care?** Within the UK everyone has a General Practitioner as a central point of contact. However, they are not very good at handling complex conditions/care and have no control over social care systems. The Alzheimer's Society may play an important role in the future. In the meantime integration of both health and social care is reliant on family carers. Though the role of the family carer is continuously changing, often people have to take on the role as a "care manager" to resolve all care issues. Recognising this role can be quite difficult and stressful for these relatives, but it is important to acknowledge that some carers can find positive meaning from this role.



PROF KI WOONG KIM, DIRECTOR KOREAN NATIONAL INSTITUTE OF DEMENTIA

### P2. PRESENTATION SUMMARY

The prevalence of dementia is on the rise and is one of the biggest health and social care challenges we face globally. In Korea alone, the number of people with dementia is estimated to increase by about 450% by 2050. Currently there are an estimated 0.6 million people with dementia in Korea and this is set to double every 17 years. By 2025 the number of people with dementia in Korea will exceed the number within the UK. Dementia incurs an enormous expense in Korea. In 2013, the annual national dementia cost was about 10 billion USD. This was about 0.7% of its GDP. This is set to rise, with 2% of Korea's GDP being spent on dementia by 2050.

Dementia is becoming the most feared disease in Korea. It is more feared than cancer in older age groups and is the second most feared disease after cancer in younger age groups.

To combat the increasing prevalence of dementia two National Dementia Plans, one in 2008 and one in 2012 were developed in Korea. The focus of the first plan was prevention and early diagnosis, development and coordination of infrastructures and management, and improving awareness. The 2<sup>nd</sup> plan also addressed these points but had more focus on supporting family members. The Dementia Management Act (DeMA) was enacted in 2012 to provide grounds for conducting the National Dementia Plans on a stable, organized, statutory basis.

The 1<sup>st</sup> National Dementia plan included the implementation of National Long-term Care Insurance, providing the funding to ensure that every person has timely access to relevant services and support. The National Dementia Early Detection (NDeED) programme was also introduced, which all older adults in Korea have access to dementia screening and can access post-diagnostic services including reimbursement for medication if needed. As a result, diagnosis rates have increased to 75%.

Included in the 1<sup>st</sup> and 2<sup>nd</sup> plans are other ways of enhancing diagnosis, prevention, and of supporting people affected by dementia. 'Check Dementia' a self-screening digital app for cognitive decline is available for use by the public. A National Dementia Helpline is also available, which can be used by Korean people both living in and outside Korea. Guidelines and exercises are available for the public without charge to help reduce risks associated in the development of dementia. Finally, training and education is provided to all members of the population.

To help create dementia friendly communities and increase awareness people are encouraged to become a Dementia Partner. People can become a Dementia Partner by watching an online video (30mins) and completing a quiz. Additional training can be completed to allow people to volunteer as a Dementia Partner Plus.

The aim of the 3<sup>rd</sup> National Dementia Plan is to create a dementia friendly society where people with dementia and their carers can live well. The objectives of this plan are to focus on prevention and management, convenient diagnosis, treatment and care for people with dementia across severities, whilst reducing carer burden and encouraging more dementia research.

## P2. DISCUSSION SUMMARY

It was noted that the iterative approach of the Korean National Dementia Plans, which have such depth and breadth, is compelling.

**How is impact on the individual measured?** Previous National Dementia Plans were sparse in outcomes – diagnostic rate, rate of participation etc. Quality of life was not measured in previous plans, but will be in the future.

**How are Korean dementia services funded?** Everyone who earns money pays into the Long-Term Care Insurance programme (aged 20+). Contributions are 6.55% of their national insurance payment which is about 6% of salary.

**How many people with dementia are screened?** Out of six million people over the age of 65, two million get screened. One third of the two million go onto the next stage and get a diagnosis at a government run centre. Two thirds either are too mild to get a diagnosis, go to private centres, or do not seek help. In the end 25% of those screened are diagnosed with dementia.

**Can you provide more details on the National Dementia Helpline?** The helpline provides information on practical support available as well as emotional support. Approximately 20% of people that call ask for advice on methods of caring and emotional support. People can approach the National Dementia Helpline via its online presence or through a mobile phone app 'Companion'.

**There is evidence that the age related prevalence of dementia is decreasing in UK/US, is it the same in Korea?** The prevalence of dementia in the young-old is decreasing but increasing in the old-old. In part, this is due to a shift toward higher incidence and low mortality in Korea.

**Is it common that laws are put in place to achieve health outcomes in Korea?** This is not common. However, the Ministry of Health and Welfare had a strong commitment to improving dementia care and therefore facilitated the formulation and adoption of the new law. Laws had only been made once before, for the Korean Cancer Care Plan.

**What are the current challenges for Korean dementia services?** In its current form the service appears to be only cost-effective in the over 75s. It is thought that this is because younger people, who will often have less cognitive impairment, do not get detected. Similarly to the UK model, there are some issues integrating healthcare and social care providers.

**How long does it take for a person to receive a formal diagnosis after screening in Korea?** On average it takes two weeks, but service users can get a formal diagnosis quicker if needed.

## P3. DEMENTIA RESEARCH IN THE UK

JAMES PICKETT, HEAD OF RESEARCH, ALZHEIMER'S SOCIETY

### P3. PRESENTATION SUMMARY

There is a strong focus on dementia research in the UK, particularly in the pursuit of finding a cure, treating symptoms, and delaying progression. There is also a broader focus by bodies such as the Alzheimer's Society into areas such as research into care and reducing burden. The focus of producing good quality dementia research is a core objective of the Alzheimer's Society and has also been highlighted by the National Dementia Strategy and the Prime Minister's Dementia Challenge. To enable growth of dementia research in the UK, funding for dementia research has increased over the past few years, with the government contribution doubling and the contribution from the Alzheimer's Society increasing tenfold. Approximately £90million was spent on dementia research in the last year.

There are several government programmes and charities which provide funding for dementia research, however, these bodies do not necessarily have the same aims and goals and do not necessarily work together to create an integrated research network.

The different types of research occurring in the UK are:

- Basic research - Understanding the core mechanisms that cause neurodegenerative diseases
- Translational research – The application of findings from basic research to enhance health and wellbeing.
- Applied research – There is a lack of large scale research which applies findings from previous research, there needs to be more implementation research

There is an aim in the UK to create a "super cohort" from a number of individual longitudinal studies. This could be used, among other things, to see the effects of interventions on people with different genotypes of the APOE e<sub>4</sub> allele.

Initiatives are underway to enhance dementia research in the UK to make it world leading. Join Dementia Research (JDR) is a network that has been set up to enable people with dementia to sign up to dementia research. Surveys suggest that approximately 80% of people would want to take part in research. A notable research project that is currently underway is the 100,000 genomes project. This project aims to increase our knowledge of rare illnesses by offering the next 100,000 people with a rare illness to have their full genome

sequenced. There are currently plans to create a Dementia Research Institute, which would be the equivalent to the Deutsches Zentrum für Neurodegenerative Erkrankungen (DZNE) in Germany.

Volunteers play a vital role in the research process. The use of Patient and Public Involvement (PPI) groups are instrumental in dementia research. In the Alzheimer's Society these groups are involved in all aspects of the research process such as making decisions on grant applications and providing additional support following funding.

### P3. DISCUSSION SUMMARY

It is important to note that within the UK local areas make decisions on implementing services, which presents specific challenges in research being translated into practice.

**How crucial are Brain Banks Network in the UK?** Just collecting brains has limited value alone. To provide value to researchers the collection of routine clinical notes and imaging data is needed and this is underway in the UK.

**Could you summarise the level of support for dementia research in Korea?** There needs to be increase dementia research funding and infrastructure in Korea. At present, some elements of clinical research are well established, but there is limited infrastructure for biomedical research.

Comparatively, UK research culture is more developed (if not consistently across all areas) but people can see the benefits and return. Cancer research infrastructure is very big, dementia research will need develop to match this if we are to deliver similar advances.

There is a gap in research into the use of assistive technology in dementia. In both the UK and Korea, people that create the technology are concerned in the development of the technology, but less on evaluating the impact on the patient. The Alzheimer's Society is conducting research in the use of telecare aids (online) which are able to support people with dementia. This is a collaboration between the technology companies, clinicians and users.

## P4. DEMENTIA SUPPORT POLICY AND THE ROLE OF THE LONG-TERM CARE INSURANCE IN KOREA

DR AE-JUNG YOO, RESEARCH FELLOW, HEALTH INSURANCE POLICY RESEARCH INSTITUTE, KOREAN NATIONAL INSURANCE SERVICE

### P4. PRESENTATION SUMMARY

The Long-term Care Insurance (LTCI) system in Korea was implemented in 2008 after 7 years of preparation. Only five countries in the world use this type of insurance system, these are: Germany, Luxembourg, The Netherlands, Japan, and Korea. The Korean system is similar to the system of Japan. Every working person from the age of twenty contributes to LTCI. The need for the introduction of the LTCI system arose through an increasing elderly population and a change in family structures, this impacted the medical costs of people living with chronic illnesses. In Korea the healthcare system and LTCI co-exist. Long-term care is financed through insurance contributions (60-65%) and government subsidy (20%) with the person covering the rest (15-20%).

Beneficiaries of LTCI are people over the age of 65 but also people under the age of 65 with illnesses such as dementia and stroke. To deliver care services to people, an assessment process is undertaken, nurses and social workers work together to assess the needs of the person and give them a grade of 1 (more serious) to 5 (less serious). People are assessed on functions such as activities of daily living (ADL) or instrumental activities of daily living (IADLs). People are provided with a care plan and can then choose to go into a care home or choose another care system such as home care.

With an aging population and an increase in dementia prevalence the number of people using the benefits of the LTCI has increased over the past eight years, as has the number of care facilities and home care centres. The challenge for the LTCI are how to improve the quality of the services.

The Dementia Support Policy aims to provide support to people with a grade 5 who have mild dementia with no or little physical impairment and therefore do not qualify for the LTC service. Support can include, day and night care, cognitive stimulation training by trained staff, and a holiday system for families aimed to provide relief from burden for caregivers. The implementation of "dementia incentives" when assessing the grading of people allows for the inclusion of caregiver burden as a factor when grading.

There are however problems in the Dementia Support Policy with the need for a management system, standardisation of professional services, and more professional education. Future plans for long-term dementia care in Korea include expanding current services and reinforcing professionalism in service providers. This will include building a high quality workforce and enhancing the education offered to workers on the job.

Korea has the energy and funds to implement this system rapidly, however, there are still concerns about the needs of the aging population.

#### P4. DISCUSSION SUMMARY

**What is the sustainability of the Korean system?** It is government protected. Currently, it is financially in the black and is not controversial as a tax.

**How consistent has the government subsidy been?** There may be a need to renegotiate with government in the future.

**What percentage of insurance deductions go toward the LTCI?** Individuals pay 6.55% of their national insurance contributions for the LTCI.

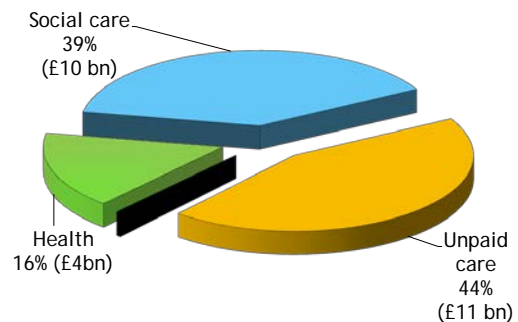
**Are there similar work force problems in Korea as in the UK?** Yes. There are also negative views toward professional carers, but they are trying to improve the social standing of these carers.

## P5. THE ECONOMICS OF DEMENTIA CARE

MS ADELINA COMAS-HERRERA, ASSISTANT PROFESSIONAL RESEARCH FELLOW,  
LONDON SCHOOL OF ECONOMICS

### P5. PRESENTATION SUMMARY

The costs of dementia care are going to increase. The total cost of dementia in the UK is £26.3 billion with 39% covered by social care, 16% by healthcare and 44% covered by unpaid care. Social care is funded by the local authority (local government) or the individual, currently, individuals and their carers “fund” two thirds of resources for dementia care. The costs of dementia care vary according to the degree of severity and to care setting. For example, if the cost of unpaid care if factored in, it may be cheaper for people with severe dementia to live in residential care rather than the community.



The costs of dementia in the UK (Estimates by PSSRU for *Dementia UK: 2<sup>nd</sup> edition* (Prince et al, 2014))

Despite the welcome reports decrease in age-specific prevalence, the total number of people with dementia will increase due to larger numbers of people reaching older ages, which will in turn result in increased reliance on unpaid carers and health and social care costs. The key question remains: how can we meet the future needs of people with dementia and their carers? We can potential reduce the numbers of people with dementia by minimising risks and managing chronic health conditions better. We can provide more robust financing, and we should aim to spend well on dementia by reducing the “bad” costs such as late diagnosis and poor care, and increasing the “good” costs such as appropriate treatment and responsive personalised care.

Spending well may be achieved by using evidence from research. The MODEM project is a collaboration between The London School of Economics and the Universities of Southampton, Newcastle, and Sussex, and the International Longevity Centre-UK. It involves a systematic mapping of the evidence on dementia care and treatment interventions and a comprehensive approach to modelling outcome and cost impacts of evidence-based interventions for dementia. The models project the future costs of dementia under the current arrangements up until 2040, and using information on how costs and outcomes vary, we will model



how costs change if evidence-based interventions are widely implemented. As an example, two interventions of interest are cognitive stimulation therapy (CST) and START (a psychosocial intervention for carers), both of which have good outcomes and are more cost effective than standard care.

## P5. DISCUSSION SUMMARY

**Spending the same amount of money but achieve better outcome vs spending less money to get the same outcome. Which is preferable?** That would depend, where there is a need to improve the current level of outcomes (which is usually the case in dementia care and treatment), there is a strong argument to at least spend the same.

**We are not very good at measuring carer costs, what should we do?** The time spent caring eventually has an impact on the care provided and on the carer's quality of life. Day care may be an effective way of keeping people living in the community, not only from the perspective of the person with dementia but also on the carer. The cost of unpaid carer time is a real cost of dementia as they could be doing other things during this time.

**What are the difficulties in changing the current system to have more day care?** We have little evidence on the effects of different care provision (nurse vs home help) in terms of outcomes.

In the 1980s it was shown that day care was a cost-effective method of providing care and support. However, since then day care has changed. It used to run by local authority/government and free to service users, now it is perceived to be expensive because access is usually means tested. Most carers are unable or unwilling to pay.

It is important to note that home care is not a substitute for day care, particularly because home care is often limited to instrumental support due to a lack of funds.

## P6. THE CHALLENGE OF METROPOLITAN/PROVINCIAL DEMENTIA CENTRES OF KOREA

MS EUNAE SIM, RESEARCHER, KOREAN NATIONAL INSTITUTE OF DEMENTIA

### P6. PRESENTATION SUMMARY

The Dementia Management Act 2012 of Korea required the creation of the National Institute of Dementia and Metropolitan/Provincial Dementia Centres to generate and carry out dementia management plans throughout the country. Thirteen centres have been established so far, with a plan to open four more by the end of 2016 so every region in Korea has a Metropolitan/Provincial Dementia Centre.

Metropolitan/Provincial Dementia Centres work with organisations such as the Korean National Institute of Dementia and local government. To fight against dementia, Dementia Centres provide education to healthcare professionals and conduct research into care and treatment. Dementia Centres also support local governments to establish and run dementia management programmes, to provide education and training and improve awareness and understanding of dementia through awareness campaigns such as the national walkathon and Dementia Partners. Dementia Centres have programmes specialised for each region.

Another specialised programme is running the Regional Dementia Council. These councils advise and support local government to create and operate regional dementia management plans. Provincial councils meet quarterly and are inclusive of numerous organisations and people. Metropolitan Dementia Councils meet six times a year and includes government officials and welfare service providers.

These regional dementia councils are important for the implementation of the 3<sup>rd</sup> National Dementia Plan. To make this Third National Dementia Plan successful, challenges identified by dementia centre directors need to be addressed. The challenges faced currently include: difficulty in recruiting members, a lack of shared priorities, and a lack of understanding of the roles of the council. We are therefore grappling with how we can invigorate the regional dementia councils and how we can support non-profit organisations such as Korean Association for Dementia, who provide services to people with dementia and their families.

### P6. DISCUSSION SUMMARY

**Is the network of dementia centres sufficient?** The 17 centres are sufficient in terms of administration. However, there may need to be more in the future particularly in the busiest centres.

**What are the Councils' powers?** These councils do not have a budget. They do however provide a networking role. They are not empowered to influence the Dementia Plan, but rather engage stakeholders, disseminate information and execute efficiently the region's dementia management plan.

**What can we learn from the UK Dementia Action Alliance?** Bringing together organisational support can be very helpful. Delivery at a national and local level remains patchy in the UK but these alliances can help drive up ownership and quality. It is important to recognise that understanding and supporting people with dementia is beneficial and that they can influence national policy. People with dementia have the right to have a voice and these alliances can help that be heard.

**What is the Korean education system for dementia?** There is a standardised dementia education manual for nurses, social workers, and doctors as well as the general population for dementia. The aim is to provide a gradient based knowledge depending on role.

**How did you get the community and business willing to engage in dementia-friendly communities?** The Alzheimer's Society have identified that there are tiers of knowledge that people should have based on their likely contact they have with people with dementia. Creating a dementia friendly community should be the end goal of these groups led by its members. Media can play an important role of highlighting dementia and facilitating the attitudes and understanding need for dementia friendly communities.

## P7. ARE WE A RESOURCE-POOR SETTING TOO? CHALLENGES IN IMPROVING THE COVERAGE AND QUALITY OF CONTINUING CARE FOR PEOPLE WITH DEMENTIA IN THE UK

PROF MARTIN PRINCE, PROFESSOR OF EPIDEMIOLOGICAL PSYCHIATRY, KING'S COLLEGE LONDON

### P7. PRESENTATION SUMMARY

Low and middle income countries have challenges with dementia diagnosis and care, with poor use of health services by people with dementia and no continuing care. There is a tendency or expectation to rely on family systems to support people with dementia and there are no structured services to support informal care. Comparatively, in high income countries there is a focus on dementia diagnosis, though dementia coverage is poor. In the UK, diagnosis rates vary between 43% and 75%, waiting lists for diagnosis vary between 2 weeks and 4 months, whilst receiving the results from assessment can take up to 40 weeks. Can some of the things we learn from developing nations be applied here?

Projects such as the PRIME, WHO I-COPE and Goa COPE are trying to improve diagnosis and support for people with dementia and other mental health conditions.

The PRIME project sets out to generate evidence on the implementation of the integrated packages of care for mental illnesses. These packages work across three levels:

- Healthcare organisation
- Healthcare facility
- Community

It has been found that half a day's training is sufficient to allow people to detect someone with cognitive impairment, whilst a 7 item cognitive screening test is able to be used to identify probable dementia. The WHO I-COPE project also identified that by getting carers to address impairments rather than formally diagnosing illnesses is likely to positively impact functioning and quality of life.

In Goa people with dementia and their carers were not happy with services accessed, while health workers wanted to help people in the community but felt they did not have the skills. The Goa COPE project allowed for the implementation a COPE style service in Goa. It was found that community health workers were able

to accurately detect a health problem (e.g. nutrition problem) vs the clinician. It was found that by implementing this COPE style system there was a mean improvement of 6% in body mass in nutritional study, with a high effect size. The data suggest that this would be of benefit to people with dementia.

## P7. DISCUSSION

**Should we be placing more responsibility on less specialist services?** Yes. We cannot undo specialist services in the UK, though post-diagnosis we are under resourced and this would be very applicable. There is a need for role clarity and for the primary care role in the management of people with dementia post-diagnosis to be developed, owned and delivered. There is an increasing acknowledgement that not everyone needs diagnostic imaging to make a diagnosis of dementia or to attend a memory clinic.

We know very much more about dementia now that we did just a few decades ago. The number of publications on dementia is increasing exponentially and the knowledge and information that is revealed through these studies are very helpful to formulate new strategies and the ways to assist the people with dementia and their carers. The data collected show that the number of people who are affected by dementia is rapidly growing and will continue to increase. The data also reveal that the societal cost of dementia exceeds that of diseases that were addressed in the 20th century such as cancer, diabetes, or heart disease.

Recognizing the seriousness of dementia, countries have started to build national dementia strategies. It is striking how the strategies from different countries all share themes. They identify the needs to change public and professional attitudes and understanding of dementia; to improve diagnosis making the procedure beneficial for individuals; and to improve the quality of the continuum of care needed by people with dementia.

To be effective, all strategy needs operationalisation and delivery. For national dementia strategy, there is a need for a number of goals to be pursued simultaneously. Dementia is feared and fear makes people avoid talking about it. The myth that prevents people from discussing about dementia or seeking help when needed is a belief that dementia is a normal part of aging and therefore, nothing can be done. This fear can be dismantled by simple acts such as the Dementia Friends or Dementia Partner initiatives. What Japan did by changing the word for dementia that hitherto contained negativity towards illness to the one that denoted neurocognitive disorder neutrally is an example that shows how simple things can make a big difference. In the UK, funded by the Department of Health, the Alzheimer's Society designed a 'worried about your memory' campaign. This was an exceedingly successful public information campaign that gave clear and simple information on dementia and allowed people to seek help and encouraged doctors to be part of the process of delivering help.

In terms of better diagnosis of dementia, it is important because knowing about the condition can possibly assist individuals with dementia and their families in making necessary and the best choices for themselves.

When people know what is going on in an early and timely fashion, it can help them prevent harm or crisis less that might lead them to unneeded admission to hospital or long term care.

In terms of better prevention and treatment of dementia, in the UK, it appears that through the cardiovascular public health messages that have been delivered in the past 30 years that there has been a small decrease in the prevalence in the number of people with dementia in certain age groups. Improving treatment for people with dementia does not only require new pharmacological intervention but also delivering the positive psychological, social, educational and support services that we already know can help to allow people with dementia to live well with dementia, to all that might benefit from them.

## SEOUL P1. DISCUSSION

**It seems there is stigma for dementia in Korea. What are being done to change people's understanding or dissolve stigma about dementia?** A lot can and needs to be done to raise awareness on dementia and the methods to achieve this can differ by country. For example, Japan changed a word for dementia. However, a vital element of any dementia strategy is to change positively people's beliefs and ideas on dementia. Other positive examples are the Dementia Partner and Dementia Friends programmes and the increasing positive messages that are part of the media coverage of dementia.

**As the society ages, a nation's burden of medical cost from dementia inevitably increases. What are the policies in England to tackle these issues?** The burden caused by older frail people in general and people with dementia in particular is a clear pressure on health services. In terms of policy the Department of Health (DH) has the National Dementia Strategy and the subsequent Prime Minister's Challenges on dementia to guide improvement. The focus is on prevention of care home and general hospital use by earlier better diagnosis and better aftercare and support after diagnosis through to the end of life. General health care policy is looking at integration of health and social care and ways of treating people outside hospital and preventing admissions.

**Are there any longitudinal changes in England's dementia prevalence rate? For example, is vascular dementia decreasing and Alzheimer's dementia or Lewy Body dementia increasing? What are the causes of these changes?** We do not have direct evidence on what is happening with subtypes of dementia. The best data we have are summarized in the website: <https://www.alzheimers.org.uk/dementiauk>.

## SEOUL P2. THE ROLE OF THE ALZHEIMER'S SOCIETY IN PUBLIC POLICY AND QUALITY IMPROVEMENT IN DEMENTIA

MS CHRISTINA WYATT, REGIONAL DIRECTOR SOUTH EAST, THE ALZHEIMER'S SOCIETY

### SEOUL P2. PRESENTATION SUMMARY

In 2009, the UK's Department of Health (DH) published its first National Dementia Strategy for England. The dementia strategy contained 17 recommendations that were categorized in three following areas: 1) raising awareness and understanding, 2) early diagnosis and support, and 3) living well with dementia.

The Alzheimer's Society has worked closely with the DH over the past five years. The Alzheimer's Society strives to improve the care and support for people with dementia and diagnosis rates have increased by 20% since 2010. The Alzheimer's Society has provided dementia-awareness training for about 450,000 NHS staff and 100,000 social care workers. It has been involved in the development of 82 dementia-friendly communities and the recruitment and training of 1 million Dementia Friends. It invested more than £9million in research in 2014/15 with the commitment to spend £10million on research each year going forward. However, even with the work accomplished and efforts since 2009, the Alzheimer's Society's annual survey found that nearly one third of people with dementia think they were not living well with dementia. Moreover, more than half of GPs reported that their patients were not receiving enough support from the NHS or adult social care.

Responding to these needs and services gaps for people with dementia, the Alzheimer's Society has developed the following approaches. First, to help people with dementia and their carers to be able to talk about their concerns, more Dementia Advisers to help them to be connected with community resources and social networks are needed. Second, to make all health and social care settings more dementia friendly, care homes and hospitals need to strive to be more integrated into their community and community services that can meet the care needs of people with dementia. Third, to increase dementia awareness through dementia education, a dementia training quality mark that can be adopted by both health and social care needs to be developed. Fourth, to create communities that are more dementia friendly, collaboration with local partners and support from local political leaders is essential. Lastly, the UK needs a national and long-term plan for dementia research to increase its funding to reflect dementia's importance and impact on society.



Moving forward to achieve the goals mentioned above, the UK needs to produce a national action plan for dementia with secure funding. In doing so, the following needs to be included: 1) capitalising on the improvements which have been made and build on improved diagnosis rates to deliver better care; 2) producing a national plan to deliver the Prime Minister's Challenge on dementia 2020; 3) mapping out how the plan will be funded and securing funding from the Spending Review; and 4) deciding who will be responsible for the delivery of the action plan.

## SEOUL P2. DISCUSSION

**In many cases, going to the hospital is difficult for the people with dementia. What services are there to help people stay at home?** There are a large number of services that have been developed to enable prevention of admission to and facilitation of discharge from general hospitals. Specialist psychiatric services treat people in their own homes. Social services provide home care that is designed to support people at home and prevent admissions to care homes.

**It is understood that in UK, people become and act as Dementia Friends and Dementia Friends champions voluntarily. In Korea, people do not pay much attention unless the accredited organizations officially recognize such a program.** The reasons why voluntary programs are successful in UK vary. The Alzheimer's Society advertised its programs in the media and included personal stories and experiences that show what it is like to live with dementia and care for the family members who have dementia. This strategy stirred up the interest among the general public that dementia could occur in their families. Also, the UK government supported this initiative as the Prime Minister David Cameron and Members of Parliament became Dementia Friends. It appears that the public have a need and desire to know more about dementia.

## SEOUL P<sub>3</sub>. UNDERSTANDING THE GLOBAL AND NATIONAL CHALLENGES OF DEMENTIA

PROF MARTIN PRINCE, PROFESSOR OF EPIDEMIOLOGICAL PSYCHIATRY, KING'S COLLEGE LONDON

### SEOUL P<sub>3</sub>. PRESENTATION SUMMARY

Dementia is becoming the preeminent epidemic of the 21st century. To promote the collaborative effort that is needed to solve this issue of dementia worldwide, it is important to have a global picture of dementia and dementia care. Since 2013, the G7 countries (formally the G8) have focused on dementia bringing global attention to dementia. Over the last two years, the G7 has completed six legacy events that led to the first World Health Organization Ministerial Conference on Global Action Against Dementia (GAAD) in March 2015. A call for action was signed by 88 countries and a commitment was made to the establishment of a global observatory for dementia.

Funded by Alzheimer's Disease International, King's College London established a Global Observatory for Ageing and Dementia Care and has published the ADI World Alzheimer Reports since 2009. The 2015 World Alzheimer Report estimated the number of people with dementia as 46.8 million worldwide. This will increase threefold by 2050 reaching 131 million, with nearly three quarters of all people with dementia living in the global south of low and middle income countries. It is estimated that there are ten million new cases of dementia every year, which means there is a new case every three seconds.

In 2015, the global societal economic cost for dementia is 817 billion US dollars and is projected to exceed 1 trillion US dollars in just two years' time. The numbers of people living with dementia will double every 20 years, but the cost of dementia will double every 13 years. In the next 35 years, the majority of new cases of dementia will be from developing countries such as Brazil and China and it is important to understand that the cost of dementia will also increase rapidly in those countries.

To solve the challenge of dementia, a public health orientated approach is needed that emphasises brain health promotion and dementia prevention. The message should include the following: 1) dementia is a preventable condition and managing risk factors can reduce incidence; and 2) dementia is everybody's business and it is never too early or too late to start working to reduce the risk of developing dementia.

A continuum of services from diagnosis to end of life care are necessary to support the people with dementia and their carers. However, there are major concerns that changes in traditional family care systems, delayed dementia diagnosis, and the lack of continuity and integration of services that exists in all parts of the world are challenging timely and appropriate service provision. Low and middle income countries have few health specialists or primary care service that can reach people. Therefore, an imaginative approach is needed to create accessible services with equitable access to care regardless of location or wealth. Emerging models of enhancing generic community health care services suggest that it is possible to generate integrated services that are holistic and person-centred, but which are also sustainable and cost effective.

### SEOUL P<sub>3</sub>. DISCUSSION

**The 2014 World Alzheimer Report discussed dementia risk reduction. What is the most effective and the most feasible method for dementia prevention? Further, if each country effectively manages dementia risk factors, how much would you expect the global incidence rate and prevalence rate to fall?** These are very pertinent questions and are addressed in detail in the report. The responses to these questions are included in the following publication: <http://www.alz.co.uk/research/world-report-2014>.

**Care for dementia is deemed as important as treatment. Korea seems to pay more attention to diagnosis and clinical treatment. In UK, do people with dementia receive non-pharmacological treatment?** As mentioned in the presentation, globally we lack evidence-based care services. Support and education for carers is a particular area that needs to be strengthened and increased. Health care is free in UK but it is difficult to provide all types of services for everyone. The solution might be expanding the role of primary health care services. The biggest challenges to implementing this would be agreeing the development and extension of roles and securing the funds.

**In the UK, what has been done for dementia prevention?** In the UK we know what needs to be done to reduce the risk of developing dementia. However, getting these messages across is more complicated. UK public health services have developed a mobile application that allows one to complete a self-check on brain

health and the chance of developing dementia. There is a need for more research on how to encourage the public to practice actions that can prevent dementia.

## SEOUL PANEL DISCUSSION

**Kim, Ki Woong, Director, Korean National Institute of Dementia.** It is time to understand how dementia is a serious issue worldwide and to think about how Korea could contribute its experience and knowledge to solve the problem.

**Yoo, Ae Jung, Research Fellow, Health Insurance Policy Research Institute, National Health Insurance Service.** Services and programmes need to be created based on the principles of person-centred care. We need consider how long-term care can provide services that make the most of life for a person with dementia. One of the major aims of our funding streams is decreasing the admission rate to care homes. To accomplish this goal, improved awareness and understanding of dementia is deemed crucial so individuals with dementia can stay longer in the community.

**Jhoo, Jinhyung, Secretary General, Korean Association for Dementia.** The National Dementia Strategies for England and Korea have many similarities in their content and implementation. Korea needs to increase the participation of public and private organizations such as the Korean Association for Dementia. Early diagnosis and treatment is a key for dementia. In Gangwon province, early diagnosis is well established and tries also to provide support for the families of people with dementia, offering support programmes at no charge. On the other hand, case management for individuals with dementia need to be improved and more Dementia Partners are wanted.

## WEBLINKS

100,000 genome project	<a href="http://www.genomicsengland.co.uk/the-100000-genomes-project/">http://www.genomicsengland.co.uk/the-100000-genomes-project/</a>
Alzheimer's Society UK	<a href="https://www.alzheimers.org.uk/">https://www.alzheimers.org.uk/</a>
Alzheimer's Disease International	<a href="http://www.alz.co.uk/">http://www.alz.co.uk/</a>
Dementia Action Alliance	<a href="http://www.dementiaaction.org.uk/">http://www.dementiaaction.org.uk/</a>
Dementia Friends	<a href="https://www.dementiafriends.org.uk/">https://www.dementiafriends.org.uk/</a>
Fingertips: Dementia	<a href="http://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia">fingertips.phe.org.uk/profile-group/mental-health/profile/dementia</a>
Join Dementia Research	<a href="https://www.joindementiaresearch.nihr.ac.uk/">https://www.joindementiaresearch.nihr.ac.uk/</a>
The Korean Association for Dementia	<a href="http://silverweb.or.kr/">http://silverweb.or.kr/</a>
Korean Long Term Care Insurance	<a href="http://www.longtermcare.or.kr/portal/site/nydev/">http://www.longtermcare.or.kr/portal/site/nydev/</a>
Korean National Institute of Dementia	<a href="http://www.nid.or.kr/">http://www.nid.or.kr/</a>
Korean Statistical Information Service	<a href="http://kosis.kr/">http://kosis.kr/</a>
Korean Longitudinal Study on Cognitive Aging and Dementia	<a href="http://kloscad.com/">http://kloscad.com/</a>
MODEM	<a href="http://www.modem-dementia.org.uk/">http://www.modem-dementia.org.uk/</a>
PRIME Project	<a href="http://www.prime.uct.ac.za/">http://www.prime.uct.ac.za/</a>
UK Brain Banks Network	<a href="http://www.mrc.ac.uk/research/facilities/brain-banks/">http://www.mrc.ac.uk/research/facilities/brain-banks/</a>
Link to Seoul workshop presentations	<a href="http://www.nid.or.kr/dementia_center/greeting/newpage10.asp">http://www.nid.or.kr/dementia_center/greeting/newpage10.asp</a>
Link to London workshop presentations	<a href="https://www.bsms.ac.uk/research/cds/presentations/uk-korea-symposiums.aspx">https://www.bsms.ac.uk/research/cds/presentations/uk-korea-symposiums.aspx</a>