

10/66 Dementia Research Group is part of Alzheimer's Disease International

New centres join 10/66

With 12 population-based study centres in 10 countries, 10/66 studies already cover many world regions. New centres would like to join the 10/66 program, but funding, training and technical support are always an issue.

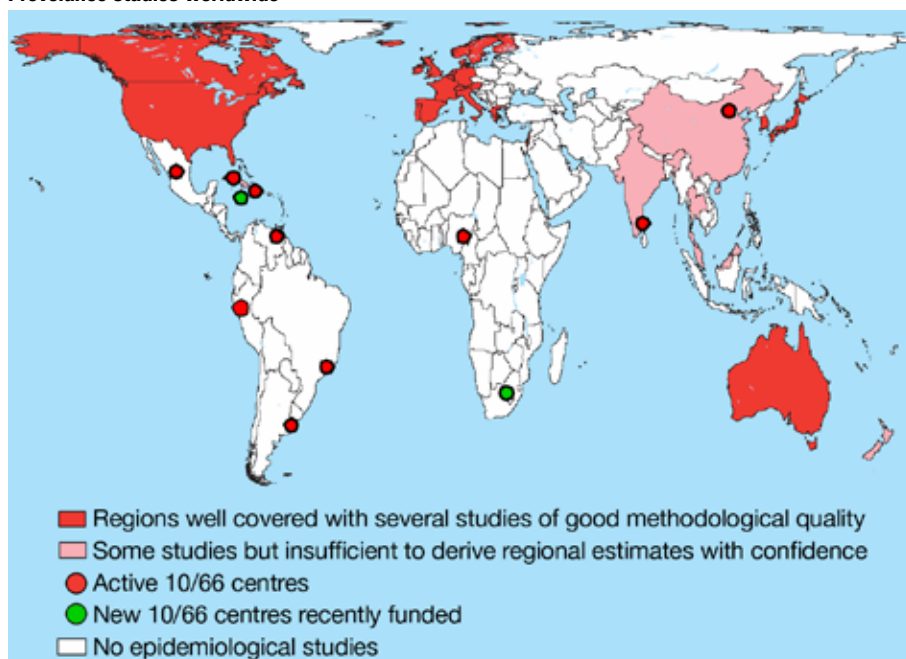
Researchers representing possible new centres in six countries; South Africa, Taiwan, Puerto Rico, Kenya, Portugal and Spain joined us in August for a training session.

We were delighted that Alzheimer's SA has funded Prof Malan Heyns (working with Stephen Walker and Sandra Burger at the University of Free State) to conduct the first study of dementia in South Africa, in Bloemfontein among disadvantaged Sesotho and Tswana speaking elderly. Dr Ivonne Jimenez (University of Puerto Rico) has already received support from the government for her study in San Juan. Dr Peishan Yang (National Taiwan University) has applied for government funding. Dr Manuel Gonçalves and Prof Miguel Xavier (University of Lisbon), Prof Raj Kalaria (University of Newcastle) hoping to work with Dr David N'dtei from Nairobi, and Dr Nuria Blanco (Spain) are at an earlier stage in project development and planning.

With per capita GDPs of \$25,300 (Taiwan), \$19,300 (Puerto Rico) and \$18,000 (Portugal) it is good that 10/66 is now recruiting some more economically developed centres. Older people should benefit from better resourced health and welfare systems. However, will some of the pervasive problems we have identified in low income countries – low awareness, difficulties with accessing services, services not meeting the needs of families – still apply?

Over the week in London, we were able to update the new groups with the progress of the 10/66 research programme, to offer a comprehensive training in the administration of the 10/66 study protocols, and to discuss in details plans for implementation in each centre. 10/66 is keen to develop further projects particularly in North Africa, the Middle East, Eastern Europe and Russia; where much still needs to be done to generate an evidence base.

Prevalence studies worldwide



10/66 poster wins prize from Wellcome Trust

10/66 was invited by the Wellcome Trust to participate in its Latin American Networking meeting in Lima in February 2007. The Trust has supported many studies in the region, including our recent programme grant, and organized the meeting to learn about regional health priorities, to promote collaboration and data sharing. 10/66 was presented as one example of a successful

Latin American network. Martin Prince, Juan Llibre de Rodriguez and Daisy Acosta presented the work of 10/66. We also displayed four research posters; the one on 'preliminary results on dementia prevalence' won the best poster prize against strong competition from many excellent Tropical Medicine research projects including work on TB, HIV/ AIDS and Chagas' disease.



Editorial

Prof Martin Prince
10/66 Director

Research into policy

Research evidence, effectively disseminated, has the power to raise awareness and influence policy in progressive directions. Our research programme is now well underway. How exactly can our findings be used to advance the policy debate, and make the arguments for more and better services for people with dementia?

The first step is to raise awareness, and the media can be a helpful ally. In each 10/66 centre we will work with Alzheimer's associations to cultivate contacts with journalists. 10/66 researchers have already succeeded in getting the message out in newspapers, TV and radio programmes. Policymakers read newspapers and can be held to account by media campaigns backed up by advocacy from Alzheimer associations. Throughout the project we plan to use innovative approaches, including commissioning local journalists to produce media briefings, ready to print news articles, and ready to air radio broadcasts.

Policymakers are dealing with many competing priorities. They appreciate and act upon simple, clear, authoritative information. In the UK and Australia, reports on dementia commissioned by the associations used research evidence to estimate numbers of people affected, trends over time, access to health and social services, and the individual and national economic cost. These attracted much media coverage, and got dementia onto the national policy agenda. Using 10/66 data we will produce similar reports for the Latin American region, and contribute to an ADI sponsored 'World Dementia Report'. We need to engage with policymakers directly – we hope to do this nationally, by inviting policymakers to work with us on the study steering committees, and internationally by hosting a series of policymaker forums

From our work so far, two policy issues stand out, attesting to the systematic failure to provide quality health care, social and economic security for older people:

1) Primary healthcare services fail people with dementia as they focus on acute 'treatable' conditions and are clinic-based. 10/66 has found that poverty, old age and dementia are barriers to receiving healthcare, across all regions. Services need

to be made more responsive, and people with dementia and their families may need to be encouraged to seek help.

2) People with dementia, and their caregivers are financially disadvantaged. In most 10/66 centres, 15-25% of caregivers have cut back on work to care. In other centres (e.g. Beijing) caregivers instead choose to pay for hired help. People with dementia do not receive disability benefits and caregivers are not compensated. In India, rural China and the Dominican Republic, less than one third of people with dementia receive pensions, relying mainly on money from family instead. Modest, but universal social pensions make an enormous contribution to security in old age – people with dementia would be particularly likely to benefit from more secure care arrangements, as they would be valued for the contribution that they make to household income. Targeted disability pensions and caregiver benefits would also have an enormous impact.

10/66 and ADI will link up with the experienced policy team at HelpAge International to press for action on these issues - to secure the 'Society for all Ages' promised five years ago in the UN's Madrid International Plan for Action on Ageing.

Being an interviewer

Maria Batista (right) and Raquel Demorissi agreed that it had been a good learning experience working on the 10/66 Dominican Republic study in Villa Francisca, San Carlos, Zona Colonial. 'The surroundings were great' said Maria 'I immediately grasped that our elderly want to be listened to, especially those whose memory is fading away'. Raquel agreed 'Working with 10/66 has been a wonderful experience. Before



going into the field I was prepared to meet lonely and sad people. In fact, most of our elderly have a lot to give and are very willing to share their experiences and personal stories. I was also impressed to see how strong their faith in God is, and how much hope this gives to them'. Still, Maria pointed out that

crime and fear of crime were a big issue 'we both noticed how scared older people were; it often made our work difficult and we had to work hard to gain their trust'. Dementia was also a very visible problem 'we were soon able to pick up dementia' said Maria 'and could appreciate the needs of carers and families. Often they were struggling to deal with dramatic changes in their relative's behaviour'.

Raquel and Maria particularly enjoyed their work on the 10/66 caregiver intervention study. 'It is great that the 10/66 project will contribute to their wellbeing'

News from the centres: Dominican Republic

The Dominican Republic shares the Caribbean island of Hispaniola with Haiti. The population is 9.3 million, and 0.5 million (5.3%) are aged 65 and over. Life expectancy is 71 years for men and 75 for women. Ethnicity (white 16%, black 11% and mixed 73%) reflects the Spanish colonisation and importation of African slaves. Dominican Republic is one of the poorest and most unequal of the 10/66 Latin American countries. The per capita GDP is \$8,400. Less than one quarter of our participants received old age pensions.

Community health care is provided by the government through the system of 'primary attention units'. One doctor and one health worker serve around 750 families. Consultations are free, but medicines must be paid for. However few older participants knew of this public healthcare system, and private healthcare was widely used instead. Of those with dementia, 9% had used primary care, 19% had seen a private doctor, but more than half had used no healthcare services in the previous three months. The Dominican Republic has only twenty



Members of the Dominican Republic centre

psychiatrists, twenty psychologists and two neurologists per million population.

The 10/66 survey, of 2000 older people was carried out in socio-economically deprived districts, Villa Francisca and San Carlos in the centre of the capital city, Santo Domingo. Dr Daisy Acosta, a psychogeriatrician and vice-Chair of ADI is the principal investigator and Guillermina Rodriguez the project coordinator. The project was funded by the WHO in Geneva. It was completed successfully because of the enthusiasm and volunteerism of Daisy Acosta and her team; the medical student interviewers, Loida Gonzalez who took all of the blood samples, and the Laboratorio Nacional who processed these

without charge. The bulk of the interviews were completed by two students, Maria and Raquel, who provide their impressions on the previous page. Local community leaders publicised the project, and have helped us in disseminating the results.

Before the 10/66 survey, ADI predicted, based on prevalence estimates from other countries, that there would be 28,600 people with dementia in the Dominican Republic in 2005. Our survey results would suggest a very similar figure of 28,800 people with DSM IV dementia. However, DSM IV dementia criteria exclude many of those with less severe and recent onset dementia. Using our broader 10/66 criteria we would predict as many as 45,000 people with dementia of whom 63% would be mild cases, 25% would be moderate cases and 12% severe cases.

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How we work – the 10/66 methodology

The 10/66 group is carrying out population-based studies on dementia in 10 developing countries.

The **cross-sectional survey** is a basic descriptive study. We take a representative sample of all older residents and assess them for health status, family and living circumstances, social and economic status, lifestyles and so on. Cross-sectional surveys can be used to measure the number of people affected by dementia and other conditions (their prevalence) and their impact in terms of disability, needs for care, service use, economic cost and carer strain. We can use this information to

- Plan the need for services
- Draw public and political attention to unmet need
- Make comparisons between countries and regions
- Chart trends over time (if we repeat the survey).

In the **cohort study**:

- 1) We follow-up those who did not have dementia at baseline to
 - a) observe the rate at which they develop dementia, known technically as the incidence
 - b) investigate the causes of dementia, by following up those who are either 'exposed' (e.g. smokers) or 'not exposed' (e.g. non-smokers) to a possible risk factor and comparing the incidence of dementia in these two groups.
- 2) We follow up those who did have dementia at baseline to better understand the course and progression of the illness (changing clinical severity, disability, dependency and needs for care, caregiver strain, mortality).

Building research capacity: 10/66 PhD studentship



Dr Mariella Guerra

The Wellcome Trust has funded seven PhD studentships, through our recently awarded Programme Grant. A student from each centre will address one key research theme analysing data from all centres and working between London and their own countries. One of the first will be Dr Mariella Guerra, the principal investigator of the 10/66 project in Peru. Mariella is an old-age psychiatrist. Her PhD subject will be depression in late-life. Prevalence of depression varies widely between 10/66 centres. Mariella will be studying the effect of social and economic factors on risk for depression, in particular the role of income and food insecurity, and the effect of pensions. Mariella will be supervised by Martin Prince and Cleusa Ferri, completing her dissertation in three years for a University of London PhD. Dr Guerra is already a leading academic in Peru; this opportunity for a comprehensive research training will further develop her skills, which she can then pass on to a new generation of public health researchers in Peru.

ADI annual conference 10–13 October Join us in Caracas, Venezuela!

This is an exciting time for the 10/66 research programme. We have now completed over 15,000 interviews and assessments of older people in six Latin American countries, India and China. We have worked hard to prepare our data for first presentation in Caracas to the ADI's global network of people with dementia, carers, healthcare professionals and researchers.

Please come along and support 10/66, your research network. We need your help to disseminate our research findings. Working together, we have the power to make a difference.

Plenary

Martin Prince, the head of the 10/66 group will give an overview of our current and future research activities, and findings on prevalence, burden and access to health services

Workshop

The 10/66 caregiver intervention
Organized by Dr Cleusa Ferri, with Nori Graham, Aquiles Salas and Daisy Acosta. The 10/66 intervention is designed to educate and train caregivers, and to be administered by basic level health workers. Alzheimer's Associations should be aware of the 10/66 intervention and of its benefits and may want to:

- train their volunteers to deliver the intervention
- advocate its adoption by primary health care services in their country.

Oral presentations

Eight presentations by 10/66 investigators from Argentina, China, Cuba, Dominican Republic, Mexico, Peru, Venezuela, UK

Session A

- Prof J Llibre: Dementia prevalence in LMICs, stroke and cerebrovascular diseases risk factors
- Dr D Acosta: Dementia prevalence and early life development
- Prof Y Huang – A pilot evaluating informant questionnaire of the

community screening instrument for dementia

- Dr E Albanese: Diet and dementia

Session B

- Prof AL Sosa on MCI in LMICs

Session C

- Dr A Salas on needs for care and care arrangements for people with dementia
- Dr M Guerra on caregiver strain and depression
- Dr R Arizaga on the double burden of dementia and stroke

Posters

Five posters covering the protocols for the 10/66 population-based studies, the caregiver intervention trials, and findings on prevalence, mild cognitive impairment, risk factors, and impact on disability

- The 10/66 dementia research group population-based research program
- The prevalence of dementia in developing countries
- Subjective memory complaint and MCI prevalence
- 10/66 Dementia Research Group's randomized control trial – 10/66 caregiver intervention trial
- The risk factors for dementia prevalence in LMICs.

For details see www.adi2007.org

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