

WHO comments

1) Issues Impacting People with Dementia

- The acknowledgement of funding for research in developing countries (2.1). It is very important to stimulate these countries to do research on their own as it contributes to building a medical infrastructure of good quality
- Access to treatment at affordable prices will be an important issue in the future. There are now 140 dementia medications in various stages of trial and some will be successful and come to market over the next 3-5 years. There could be no better way of changing the psychology of the disease in these countries - i.e. there would be something positive to offer. At the moment in many lower and middle income countries anti-psychotics are used in stead of anti-dementia drugs, which is not the best option.
- Dementia needs to be recognised as a major Type 1 illness alongside diabetes, cardiovascular disease and cancer and for a way to make future generations of treatment affordable in all countries.
- Technology transfer (4.1, 4.2) could very much improve the lives of people with dementia and their families as a lot of knowledge about good treatment and care is available, but not yet used.
- Encouraging governments to invest in health-delivery infrastructure (6.1)

2) Areas of Needs Not Addressed for People with Dementia

- The role and position of patients and their organisations in the paper is very weak and it does not appear that they are a part of this process. ADI stresses the importance of inclusion of people with dementia for consultation about their needs.
- Dementia and other neurological disorders are the largest group of diseases worldwide. There is a need to make the case that the burden of dementia exists not only for patients but also for caregivers and societies. Two-thirds of people with dementia live in lower and middle income countries. There is all over the world a problem of under-diagnostic. Recently even in a country like Switzerland research showed only 1/3 of the people with dementia received a diagnosis.
- Lack of a clear vision of the role of governments, companies and NGO's: Who is responsible for which part of action?
- Lack of insight at all in the overall funding which would help determine whether the action plan can be achieved.
- The draft states that prices of medicines should be consistent with public health policies (6.3). From a solidarity point of view shouldn't this be consistent with the level of welfare of a country?
- Private sector is now spending by far the largest amount on research and development, which will collapse without a fair patent policy

- Problems with brain drains from developing countries are hardly acknowledged in the draft
- The supply side of dementia care is a big problem for care of older people in developing countries, since current services palpably fail to meet their most basic needs. New drugs for dementia won't get us anywhere unless we have capacity in primary care to diagnose the condition, treat co-morbid physical illness, and engage, advise and support the caregiver, long-term. There is a (limited) demand for these services right now, but even this is not being met.
- There is already an evidence base, from the west, for the effectiveness of some existing basic packages of care including caregiver interventions and (more controversially) for drugs for the Behavioural and Psychological Symptoms of Dementia and for community-based dementia care programmes that could in principle, with modification, be delivered at the lowest level of healthcare in the district and sub-district levels in developing countries. However, this is not happening.
- In developing countries we need to create the demand for dementia services and treatments. Raising awareness has an important role to play in getting people with dementia and their carers to use national health systems. In addition, those working in primary carer need training to identify the problem so that eventually the magnitude of the problem can be realistically measured.

3) How ADI can contribute to the plan of action (presumed that dementia will be a priority under type I diseases)

- Existing infrastructure for exchange of information, education, building capacity, sharing best practices
- Up-to-date and relevant data from the 10/66 Dementia Research Group about prevalence, burden of disease, successful interventions and health systems in a significant group of lower and middle income countries
- Experience with transfer of knowledge within our Twinning Programme
- Some initial ideas for a “Breakthrough approach” to improve care and health systems in collaboration with the International Psychogeriatric Association (IPA)
- Our global network has the expertise to propose viable and cost effective solutions. This would be culturally sensitive, appropriate for a country's stage of economic development and would fit alongside existing health/ welfare services.
- Evidence from the ADI 10/66 Dementia Research Group will be key to this. Martin Prince, head of 10/66 has just joined the WHO's Global Burden of Disease core working group on mental health estimates, including dementia, and will be able to use this position to advocate the use of evidence-based dementia prevalence figures, including 10/66, that properly reflect the burden of the disease.

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