According to a recent study conducted by the University of Oxford’s Health Economics Research Centre, dementia receives 13 times less funding for research than cancer. Yet, in 2012 alone, dementia cost the UK economy £11.6 billion – more than cancer, stroke and coronary heart disease combined.
Q: Why is there a huge disparity in research investment between dementia and other global disease burdens? What actions should be taken to tackle this funding gap?

PROFESSOR OSBORNE ALMEIDA (Max Planck Institute of Psychiatry, Germany):

Policy and decisions regarding the distribution of research spending are determined by factors ranging from dry statistics and public emotions to identified needs and scientific promise. However, it’s unlikely that low spending on dementia research reflects a general lack of concern for age-related disorders. Needless to say, besides responding to policy makers’ calls, researchers can and should be part of the decision-making process.

The apparent gap in funding for dementia research perhaps becomes less of an issue when viewed from the perspective of integrative biomedical research. While we lack treatments for dementia, we know that treatable and preventable chronic diseases (e.g., hypertension, obesity, diabetes) are causally linked to various forms of cognitive impairment. Likewise, evidence links diabetes and hypertension to depression (commonly, an intractable condition) which, in turn, predisposes to dementia. Such associations form the basis of recent international programmes aimed at delaying the onset of dementia through improvements in early diagnosis and treatment of chronic illnesses and encouragement of life-course approaches.

Without denying the need for appropriate support, more holistic approaches in dementia research could compensate for funding gaps. Abolition of the traditional divisions in neurology, psychiatry and internal medicine, and exploitation of the growing opportunities for collaboration within and across disciplines would help ensure continued progress.

PROFESSOR GERALD BERENSON (Tulane University, USA):

Funding for robust prevention of a comprehensive nature does not exist. The disparity in research investment – cancer, end-stage cardiovascular disease and instrumentation and use of drugs – remains great. Yet, prevention can cost little with big gains; the difficulty is getting physicians and the public to understand the need. The disparity in research at different levels in part relates to clinical expression of the disease: cancer, stroke and coronary artery disease have repeated and horrible clinical expression to the public, while dementia and senile changes are much more subtle. With population ageing – more individuals reaching 90 years of age, for example – these mental problems are increasing and rising to the surface of discussion.

Tackling this funding gap relates to what is more visible. We practise crisis medicine. The main problem is getting more funding for research. Prevention is an evolving complex problem, and of lower priority compared with the management of health crises.

ASSISTANT PROFESSOR PATRICK BRADSHAW (University of South Florida, USA):

I think that there is such a disparity in cancer and neurodegenerative disease research because, during the 1960s through to the 1980s, when the research budget was continuously increasing, cancer was a hot topic, in part due to high lung cancer rates associated with cigarette smoking. Many powerful people who established this system are still working in the upper echelons of government. There will not be a major overhaul of funding priorities for another 10 years, until all of these power brokers are retired and younger people, who were more affected by neurodegenerative disease instead of heart disease or cancer, are making the decisions.
PROFESSOR RICHARD CHESTON  
(University of the West of England, UK):

It isn’t just research, it’s care. There are many marginalised groups in society and we are certainly more aware now of the nature of shame and stigma surrounding dementia. It’s welcome that there are many positive moves to make it something that more people can talk openly about. At the same time, I think there is something different about dementia care in that it is threatening. There are many terrible diseases or illnesses, but dementia is unique in its ghastliness in the sense that it affects us in late age, is progressive, incurable, and challenges people’s sense of who they and their loved ones are. It is something that threatens the most immediate social relationships in their lives, leads to dependency and strips away meaning. Therefore, in all those ways, it would constitute what we would call an existential threat.

As societies, we are not particularly good at dealing with existential threats; we tend to marginalise and push them away. Furthermore, we shy away from death or deterioration. We strive to find a cure for ageing and death: the Fountain of youth, Peter Pan, Curious Case of Benjamin Button, Freaky Friday – many aspects of our cultural everyday lives feature a search or hope for a cure. It’s a recurring theme, not just in the Western world but also scientific culture.

Dementia, in some ways, personifies the very problem that society finds hardest to deal with. Therefore, perhaps it’s no coincidence that we put our money in areas that seem to be more attractive and manageable. In some ways, dementia represents things that cannot be overcome.

DR ZHIHONG YANG  
(University of Fribourg, Switzerland):

Cancer always sounds much more scary than other diseases and can touch all age groups, depending on type. Some cancers occur predominately in younger people and in children, which tends to be much more dramatic to us. In contrast, dementia mainly affects older people, as do stroke and cardiovascular diseases. Also, there are not as many options for treating cancers successfully. Although there is no therapy for dementia, affected individuals can live for many years. In general, people think that dementia is a ‘normal’ physiological process of life that goes hand-in-hand with ageing, whereas cancer is purely pathological. In my opinion, those are the reasons why cancer has received more public attention.

PROFESSOR RAMÓN CACABELOS  
(EuroEspes Biomedical Research Center, Spain):

It is obvious that most countries do not invest in dementia due to three major reasons. Firstly, people with dementia belong to an unproductive segment of the population. Secondly, the cost of dementia in the European Union is over €160 billion; 80 per cent of which are indirect costs – 10 per cent associated with pharmacological treatment. More than 90 per cent of these costs do not yield an acceptable benefit from an economical perspective. Thirdly, at the present time, dementia is a road to nowhere; therefore, investment in this field is not appealing to health administrators.

Most likely, the solution to this problem is a change in our mentality regarding dementia and disability in the ageing population. Health problems in older people are the result of both a constitutional and environmental component. We have to educate people in the necessity of prevention and the use of medical services, not only for a reparative medicine but also for a predictive-preventive medicine. If we could delay the onset of dementia by one year, we would reduce its national prevalence by approximately 30 per cent.
PROFESSOR ANDY RANDALL
(University of Bristol and University of Exeter, UK):
These figures are always different. There’s always much more funding in cancer than dementia, and also more in cardiovascular disease compared with dementia. Some of this reflects history and how society has treated these various diseases; dementia has been pushed into the corner, people got dementia but didn’t really like to talk about it because there was a stigma attached. This is pretty much going away; because of the work of our colleagues in cancer and cardiovascular research, more people are living longer and, as such, more people are getting dementia. Stigmas don’t really exist when lots of people have these diseases. The ageing population has had a big impact on this.

I think another consideration is that dementia tends to affect people towards the end of their life. Anyone would say they would rather have dementia at the age of 80 than a nasty cancer aged 20. Ultimately, though, the cost of dementia is immense. Cancer is horrible but it doesn’t cost society as much. With cancer, for example, people don’t tend to end up in residential care for long periods of time. The balance needs to be reset, absolutely, but the way this has to be done is to invest more in dementia research.

ASSOCIATE PROFESSOR RANDEL MCKINNON
(Rutgers University, USA):
In the 1960s President Kennedy declared a national initiative on space exploration leading to the first lunar landing. In the 1970s President Nixon followed this with a war on cancer that subsequently reduced the rate and improved treatment options. This, in turn, led to increased longevity and associated diseases of the ageing population, including dementia. While cancer is preventable, dementia may be an inevitable result of our success fighting these other diseases. The geriatric population does not have the same advocacy level as seen for those diseases affecting either children or adults with the social responsibilities of family and finance. However, the National Institutes of Health declared the 1990s the Decade of the Brain; healthy geriatrics are an expanding political advocacy group, and there is an increasing awareness of the need for government sponsorship to address their life quality issues. An informed, proactive and involved citizenry is the best hope for public funding to address this and any social issue.

ASSOCIATE PROFESSOR MONIDIPA DASGUPTA
(University of Western Ontario, Canada):
I believe there is a lack of knowledge about the effects of dementia or cognitive disorders on overall quality of life. People know cancer kills young people, and there seems to be a high priority on saving young people from dying. The terminal and slowly progressive nature of dementing illnesses may not be fully appreciated. Greater public awareness of the impact of dementia on quality of life, both to the individual affected and other caregivers, and how this may impact even younger persons (such as highlighting the effects of care provision on society), and costs to the medical system, may be methods to tackle the funding gap. Public awareness can result in policy change.

PROFESSOR THOMAS VON ZGLINICKI
(Newcastle University, UK):
The essential disparity is not between dementia and other age-related diseases including cancer, but between single disease-focused approaches and those that tackle co-morbid conditions as the consequence of ageing together. Only the latter has the potential to significantly improve the present situation, in which we only manage age-related disease.