



‘Recent Progress & Innovation in Dementia Diagnosis, Treatment and Care’

**A Report from the Expert Roundtable
Discussion**

July 2009

ILC-UK

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About this Report

This report summarises an expert roundtable discussion and dinner entitled *Recent Progress & Innovation in Dementia, Diagnosis, Treatment and Care* which took place on 3rd June 2009 in the Cholmondeley Room, House of Lords, London. The event was organised by the ILC-UK.

Acknowledgements

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The informal ILC-UK organising committee for the discussion and dinner comprised: Baroness Greengross, Noreen Siba, Rhiannon Freeland. The ILC-UK would particularly like to thank Andrew Chidgey from the Alzheimer's Society for his guidance and support.

The ILC-UK is extremely grateful to everyone who attended the event and for the energy, enthusiasm and expertise of all the participants.

Chair and host: Baroness Sally Greengross

Presenting speakers (in order of agenda) comprised:

Michael Hodin, Pfizer
Professor Martin Knapp, London School of Economics
Professor Clive Ballard, Alzheimer's Society
Professor Steve Iliffe, University College London
Dr Rachel Schindler, Pfizer
Professor Robert Woods, Bangor University
Baroness Susan Greenfield
Florence Lustman, Inspecteur Général des Finances, Chargée du plan Alzheimer
Professor Sube Banerjee, King's College London
Dr John Beard, World Health Organisation

Facilitators at the roundtable comprised:

Andrew Chidgey, Alzheimer's Society
Dr David Gillen, Pfizer
Andy Harrop, Age Concern & Help the Aged
Neil Hunt, Alzheimer's Society

Experts at the roundtable comprised:

Dr David Anderson, Mersey Care NHS Trust

'Recent Progress & Innovation in Dementia Diagnosis, Treatment and Care'

Mary Baker, European Federation of Neurological Associations
Andrew Bonser, Pfizer
Professor Carol Brayne, University of Cambridge
Professor John Collinge, University College London
Jacques de Tournemire, Pfizer
Dr Nori Graham, Royal Free Hospital
Dr Adam Heathfield, Pfizer
Michael Hodin, Pfizer
Earl Freddie Howe, House of Lords
Professor Paul Ince, University of Sheffield
Baroness Margaret Jay, House of Lords
Julie Jones, Social Care Institute for Excellence
Professor Christopher Kennard, University of Oxford
Dr Steve Ladyman MP, House of Commons
Baroness Molly Meacher, House of Lords
Baroness Elaine Murphy, House of Lords
Dr Shaw Sorooshian, Lundbeck UK Ltd
Lord Anthony St John, House of Lords
Baroness Glenys Thornton, House of Lords
Dr Glenn Wells, Department of Health
Professor Gordon Wilcock, University of Oxford
Professor Julie Williams, Cardiff University
Rebecca Wood, Alzheimer's Research Trust
Professor Robert Woods, Bangor University
Jeremy Wright MP, House of Commons.

Foreword

Dementia presents a significant and immediate challenge to us all. While our increased longevity is a testament to our advances and development as a society, this success has conferred additional responsibilities which as a society we cannot and should not ignore.

Currently there are 700,000 people with dementia in the UK and this will rise to over 1 million people by 2025 and 1.7 million by 2051. One in three people who survive to 65 will end their lives with a form of dementia. The National Dementia Strategy in England published in February of this year signalled a sign of hope, setting out a road map for improvements in dementia services - the effective implementation of the identified 17 key objectives will be critical if the strategy is to serve as a catalyst for meaningful and lasting change.

Against this backdrop, an expert roundtable discussion and dinner was planned in June 2009 to discuss recent progress and innovation in dementia research, diagnosis, treatment and care. This meeting forms the basis of our report which I hope will highlight priority issues, particularly in light of the forthcoming dementia research summit on the 21st July 2009.

I would like to thank all those who took part in the expert roundtable dinner and discussion for their enthusiasm and commitment and I do hope this report provides a platform for further collaboration, discussion and ideas, which will lead to a programme of action.



Baroness Greengross OBE
Chief Executive, ILC-UK.

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Introduction

The expert round table discussion and dinner on *Recent Progress and Innovation in Dementia, Diagnosis, Treatment and Care* was held on the 3rd June in the House of Lords. The round table provided a unique opportunity to bring together some of the leading experts on dementia from across the UK and Europe to debate and discuss some of the priority issues on this critical agenda.

The format of the evening included: welcome and introductions, presentations on some of the main issues identified; open debate and facilitated breakout sessions over dinner to prompt and direct further discussion. The event was convened to galvanise and garner the growing collective enthusiasm and expertise on dementia, following the publication of the National Dementia Strategy in February and stimulate further discussions and recommendations ahead of the forthcoming dementia research summit, the All Party Parliamentary Group on Dementia and a debate in the House of Lords.

This report provides a summary of the presentations and identifies some of the key themes and provides recommendations, which emerged from the roundtable discussion and debate. Speakers were given an opportunity to comment on the draft of the report, in order to ensure their comments were represented accurately.

The political and policy context behind the debate

It was a timely moment for such a debate, as dementia is no longer languishing on the sidelines of the health and social care agenda, but is now at the fulcrum of public policy debate across Europe. Last year, France's President Nicolas Sarkozy held a European dementia convention during his EU presidency in September, calling on all member states to recognise dementia as a health and social care priority. Every 24 seconds a new case of dementia arises in Europe, and most European countries are now spending approximately 1% of their gross domestic product on dementia.

In the UK there are currently 700,000 people with the condition and this is estimated to exceed 1.1 million by 2026 with the annual cost to the UK estimated to rise from £17bn to £40bn. It is thus evident, with an ageing population, we can no longer remain indifferent to the profound challenges dementia raises with regard to public health, social protection and research.

The National Dementia Strategy for England published in February of this year heralded a concerted commitment on behalf of Government to address the care and treatment of people with dementia, focusing on three key areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care. However many campaigners and charities expressed disappointment that dementia research was not an integral component of the strategy, and that the review of antipsychotic drugs has been delayed. A separate dementia research summit organised by the UK Government and the Medical Research Council, with key stakeholders and research organisations, was instead proposed which will take place on 21st July to consider a planned programme of research into dementia. It is hoped the summit will be welcomed with the same level of attention and priority that accompanied the arrival of the dementia strategy.

Despite the fact the 21st Century is widely attested to be the era of neurodegenerative diseases, the prevalence of such diseases has not been matched by comparable government investment in scientific research in this field. Funding for dementia research has consistently fallen behind cancer and heart disease in not only political, but public priorities, although the incidence of dementia is greater than both of these. The Government spends £32 million a year on dementia research, which is only one eighth of what the Government spends on cancer research.

However with the forthcoming research summit in July and the imminent publication of the long awaited green paper on the long-term reform of adult social care, the opportunity for dementia to rise from the lacunae and be at the forefront of policy development and research has arrived. There is no longer just a moral and social argument for prioritising dementia, but the economic imperative is now overwhelming and the implications for our health and social care system are profound, if we do not address the key issues of ageing and dementia in the years to come. It is no longer a case of if we should, but rather, as a society, can we afford not to?

Part 1: Overview of Presentations

This chapter provides an overview of the presentations by the chosen speakers at the roundtable.

Baroness Greengross in her position as Chair opened the event and welcomed all of the participants. Baroness Greengross stressed the critical importance of the dementia agenda, most notably for the millions of individuals and their families from across the world who are afflicted and touched by the degenerative disease.

Mr Michael Hodin, Vice President of Pfizer was invited to say a few words by the Chair. Mr Hodin emphasised Pfizer's commitment to working in partnership with a range of individuals, bodies and organisations on all aspects of dementia research and support and thanked all the assembled experts in dementia for attending.

Scene Setting

Professor Martin Knapp, Professor of Social Policy, Department of Social Policy, Director, Personal Social Services Research Unit, LSE

Professor Martin Knapp identified six areas of change with regard to dementia:

1, Changing numbers . there are approximately $\frac{3}{4}$ million people with dementia in the UK, $\frac{1}{2}$ million people with Alzheimer's disease in the UK and 53,000 new cases each year. In the next 45 years the number of people with dementia is set to rise from $\frac{3}{4}$ million to 1.7 million. This increase in prevalence necessitates immediate action to prepare for the challenges and opportunities.

2, Changing dynamics and structure of families . the question of who cares for people with dementia is essential: at present unpaid carers provide a significant proportion of the care. The cost of caring needs to be considered in terms of the advice, finances, support, training, wellbeing of unpaid carers.

3, Financial cost . at present if we consider the financial cost of caring, over a third of the total (36%) was due to informal care inputs by family members and other unpaid carers. Total costs amounted to £17.03 billion or on average £25,472 per person with late-onset dementia.

The PSSRU at LSE, in collaboration with the BBC, launched a Care Calculator and a Care Questionnaire in 2008. Part of this interactive questionnaire included a section on levels of support and funding of long term care. Out of the 10,000 people who filled in the survey, 2,500 were current users of social care and 9 out of 10 people felt the level of support they received was inadequate.

4, Changing attitudes to funding of long term care . given the changing demographics of an ageing population, if patterns of employment stay the same in the future as they are today, then there will be fewer and fewer people paying taxes and yet the demand for care is set to increase rapidly. In the same BBC survey, 80% of people said they were willing to pay higher taxes for increased spending on long term care. How the forthcoming green paper on the long term reform of adult social care addresses these issues will be critical for people with dementia and their families.

5, Changing role of social services . looked back to Peter Townsend's book *The Family Life of Old People* and compared changes in care and support for older people. Based on

dementia prevalence rates for today, but projected back to 1958/59 . fewer than 5% of all people with dementia in England & Wales were living in care homes at that time, whereas today about 30% of all people with dementia in England and Wales are living in care homes. Care homes are now front-line dementia providers, particularly during the severe stages of the disease.

6, Changing aspirations . need to consider the aspirations and expectations of people with dementia and their families, what level of care and support do they expect and what will be deemed adequate to meet their needs? How will the personalisation agenda affect and impact on people with dementia?

Current State of Dementia Research

Professor Clive Ballard, Director of Research, Alzheimer's Society

Professor Ballard opened his presentation by calling for a research strategy as opposed to a research summit. He reminded the audience of why dementia is so important, he cited the statistic that 1 in 3 people over the age of 65 will die with a form of dementia and 1 million people will develop the condition over the next 10 years.

He summarised the outputs of the following initiatives and guidelines in relation to dementia research:

1, MRC developed a strategy for neurodegeneration, not specific to dementia, which highlights the need in particular to focus on high quality basic science and to develop strong collaborative networks.

2, NICE SCIE Guidelines included research recommendations focussing in particular upon the need for better non-pharmacology treatments.

3, The Cooksey report emphasised the weakness in translational research in the UK and the need to improve the delivery of clinical trials.

However he stressed none of these strategies or recommendations were dementia specific or covered the broad range of care, cure, cause and prevention research. He was keen to stress that the UK had a strong tradition and expertise in research across a range of disciplines.

Professor Ballard also commented on the low implementation of non-pharmacological interventions with often inappropriate use of anti psychotic drugs (in an attempt to reduce disruptive behaviour instead of attempting to understand or investigate the cause of behaviour - for example, distress, feelings of humiliation or fear.) He said services were not currently fit for purpose and mechanisms need to be developed so that care services and non-pharmacological therapies with an evidence base for effectiveness are routinely implemented in clinical and care practice. He accentuated the need to encourage innovation of care services and non-drug treatments, with embedded approaches to develop robust evidence and then implement successful innovation.

With regard to pharmaceutical treatments and prevention, Professor Ballard acknowledged the use of cholinesterase inhibitors and amyloid cascade interactors had been delayed by poor prioritisation and funding issues. There are currently 4 licensed therapies (3 cholinesterase inhibitors and memantine) for the symptomatic treatment of Alzheimer's disease, but better pharmaceutical treatment was needed. Although more scientific knowledge and more refined understanding of mechanisms is imperative, he said basic science studies had already identified a number of promising treatment targets and a number of pharmaceutical treatments were already in various stages of development. Immunotherapy and dimebom are the therapies at the most advanced stage of development, but a number of other therapies targeting amyloid, tau, neuroprotection and regeneration are being investigated.

There are however only 4 treatments in phase 3 clinical trials worldwide, Professor Ballard lamented that this was a pitifully inadequate number of trials to ensure the prompt translation of scientific developments into new drugs and treatments. He said there may be specific opportunities to accelerate drug development by determining the potential utility of off-patent drugs originally licensed for other indications as treatments for Alzheimer's disease. 2 promising therapies identified in this way are already in clinical trials.

He stressed that the epidemiological evidence needed to be better understood to determine the full potential for prevention and public health initiatives. Cognitive and dementia measures needed to be included in all long term UK epidemiological and genome studies.

With regard to UK spending on dementia research, Professor Ballard said current funding was woefully inadequate. Based on the National Dementia Strategy and figures given in response to questions in the House of Commons, the annual public spend on dementia research in the UK is £27-35 million, including recent new investment. The investment in dementia research in the UK is 8 fold less than cancer research.

In conclusion, Professor Ballard stressed the need for greater collaborative working, with joint engagement by Government, the research community, charities, people with dementia and those who care for them and pharmaceutical companies to make this happen. Any evidenced based research summit would need to be followed up with a comprehensive research strategy and investment plan with a wide remit, incorporating the narrower remits of basic biology; clinical trials issues. neurodegeneration and psychosocial constructs. Professor Ballard highlighted that the UK had the most productive group of dementia researchers worldwide and with additional investment the UK was in an excellent position to make a major contribution to the international fight against dementia.

Diagnosis

Professor Steve Iliffe, Professor of Primary Care for Older People, University College London

Professor Iliffe opened his presentation by stating that diagnosing dementia was complicated, but not difficult. He said the essential problem was trying to spot new flaws on top of old in an older person and to recognise when the condition appears and how it is different from the normal ageing process. Diagnosing the sub type of disease or condition that causes dementia is however more difficult. Experienced care home managers are particularly skilled at diagnosing dementia, though over 50% of people with dementia have no formal medical diagnosis, this pattern is mirrored across many European countries. Dementia is often explained away by memory problems and there is widespread recognition that diagnosis occurs late, for example even by neighbours who spot extreme behavioural change. The median life expectancy from diagnosis is 3.5 years. yet progression may be over 10 or 20 years.

Professor Iliffe also highlighted that there are strong perverse incentives not to diagnose, for example the individual may not want their cognitive impairment labelled as dementia. Similarly a diagnosis will have implications for independence and lifestyle choice of the individual, for example driving, and psychologically they will be capitulated from having a senior moment to being diagnosed with a serious medical condition.

He also indicated a tendency for collusion amongst medical practitioners when an older person is admitted into hospital for treatment for another condition. In many instances there will be widespread recognition that the individual has dementia, but this will not be formally acknowledged. Instead the individual will continue to be described as 'confused' as opposed to receiving a clinical diagnosis, care and support tailored accordingly.

With regard to diagnosis rates and recognition by General Practitioners, a recent National Audit Office survey found that the perceived benefits of early recognition of dementia decreased as confidence in diagnosis and management increased with growing experience.

This reticence about early diagnosis, Professor Illife argued could be attributable to the fact that diagnosis is normally linked to treatment and in the case of dementia, the treatment and therapeutic options available are limited. He suggested we move away from the concept of diagnosis and treatment but look at instead recognition and response. He also suggested there could be benefits to reframing dementia within a disability model, which would facilitate a focus on all possible methods of reducing disability.

Treatment

Dr Rachel Schindler, Executive Director of Clinical Sciences, Pfizer

Dr Schindler outlined the general challenges the pharmaceutical industry face in terms of drug development, she explained that the pharmaceutical industry is investing very significantly in developing new therapies for Alzheimer's disease. There are currently over 40 potential medicines in phase II or phase III, hoping to complement the four licensed therapies that represent the only current treatment options. The medicines and research programmes being undertaken span more than 20 different biochemical pathways and interventions, and huge progress is being made in elucidating the value of these different therapeutic strategies.

She said that despite the scale of investment this number and breadth of programmes represents, there remain many uncertainties in our understanding of the disease pathophysiology. There are still no validated biomarkers to speed up research and development and it is often only in the late stage clinical trial programmes that true efficacy and clinical impacts can be tested, making the investments large and very high risk. Even in the clinical domain the uncertainties are significant. The concept of a disease modifying drug and the regulatory guidance on appropriate clinical trial design are both continuing to evolve. For many of the mechanisms being studied, it may be that earlier intervention than is currently possible would improve outcomes. Better diagnosis and support for clinical trials in prodromal patients may generate extremely informative clinical trials.

Dr Schindler stressed that the overall medical need is immense and the challenges significant, but that we had come a long way since the disease was first described in 1906. We should refrain from viewing the condition as an inevitably untreatable degenerative disorder. The prevailing medical view until the development of the cholinergic hypothesis in the late 1970s. There is the real possibility of some significant progress in the near future, with anti-amyloid therapy. Ultimately, the optimal target population for disease-modifying therapy may be prodromal AD but in any case more effective symptomatic (synaptic) treatments are needed. It takes time for fundamental research to be translated into potential medicines, but we need to advance on all fronts and create the right environment to encourage continued investment in both academic studies and commercial drug development.

Care

Professor Robert Woods, Professor of Clinical Psychology of Older People, Bangor University

Professor Robert Woods opened his presentation by stating that current care services and support were clearly not adequate or sufficient to meet the needs of people with dementia and carers. With regard to dementia he stressed that each individual's experience and journey of dementia was uniquely different and therefore their care and support would need to be tailored accordingly.

There was a specific problem with the dearth of support services following the initial diagnosis of dementia - a 'black hole' for many individuals and their families. He suggested the role of dementia advisers would require careful consideration with respect to the extent to which their role would involve brokerage, support or signposting; there was an evident need to move beyond medication being the only intervention offered following a memory clinic assessment. Diagnosis, in a psychosocial perspective, is a key intervention for the person with dementia and carers, and the content and manner of what is communicated, and the advice, information and support offered in the subsequent days and months may be key to future adaptation and coping.

The role of carers also merited greater attention and focus in public policy and research, he stressed, At the moment a significant proportion of caring responsibilities for people with dementia falls to either family members, partners, friends or neighbours and yet as a group they face multiple disadvantage for their contribution. This includes emotional, financial, health and professional inequalities. He called for greater support for carers and in particular the need to provide timely and tailored advice and guidance on support services as they navigate their way through the pathway of the disease.

Professor Woods also pointed out that the personalisation agenda in particular direct payments had not to any significant extent impacted people with dementia and their families. He said there was an extremely low up take of direct payments and there was a need for more research on the implications of rolling out self-directed support to this cohort of health and social care users.

He also highlighted there was need to look more closely at palliative care, with insufficient attention and research directed towards care and support in the final stages of dementia.

With regard to the suitability of care homes, Professor Woods referenced Peter Townsend's book 'The Last Refuge' which was based on a study of residential care for older people in England and Wales in the late 1950s. He said Peter Townsend envisaged a future society where care homes would be smaller, with a family as opposed to an institutional feel, but that despite attempts to create small, homely environments for people with dementia, the trend was again towards larger homes, and quality issues remained. He stressed that whilst there is a need for more research, there was also a desperate need, in care homes and in community services, to implement what is proven by research to work. At the present time there is schism between research and the implementation of this knowledge and learning in practice.

The French Experience and the Need for Greater European Cooperation

Florence Lustman, Inspecteur Général des Finances, Chargée du Plan Alzheimer / Coordinator of the French Alzheimer's Plan

Florence Lustman opened her presentation by stating that Nicolas Sarkozy was the driving force behind the French Alzheimer's plan, explaining that he decided to make the fight against Alzheimer's disease one of the priorities of his term as President of France. Immediately after his election he set up a Commission chaired by Professor Joel Menard, who drafted an ambitious plan, endorsed and launched by the President on the 1st of February 2008. Ever since then, Ms Lustman explained President Sarkozy had assumed a high degree of involvement in the implementation of the plan and asked her for a detailed report every 6 months.

Ms Lustman stressed that the French Alzheimer's plan was not in fact the first plan, as there were two previous plans, which focused primarily on health. The initiatives from these plans included the development of a network of memory centers and a number of day care centers and granted individuals with dementia 100% coverage of their medical expenditures. However despite these achievements, the Menard Commission recommended that action was still needed to improve the quality of life of patients and carers. The third plan was therefore conceived to address the needs of the patient and their carer, often their spouse, the intention was the plan would address all the eventualities and situations the couple would face throughout the progression of the disease.

Ms Lustman explained the plan would form a holistic and innovative approach to the growing problem of Alzheimer's in France. There would be 3 main components to the plan:

- 1, Knowledge for action
- 2, Improving the quality of life for patients and carers
- 2, Mobilising around a social issue

There would be considerable financial resources allocated to the plan, up to " 1,6 billion in new expenditure over a 5 year period, with " 1,2 billion for medical social support, " 200 million for medical care and " 200 million for research.

Ms Lustman then expounded on the 3 components of the plan.

- 1, Knowledge for action:

The overarching objective is to discover or validate a diagnosis test or a treatment within 5 years, In order to achieve this objective, a Foundation for Scientific Cooperation was set-up on June 2008 (Director: Pr.Ph. Amouyel). The aims of the foundation are to:

- build a national network of excellence
- attract the best French and foreign researchers
- develop partnerships with industry, including drug companies
- develop networks and relationships between researchers from the public and private sphere including clinical, epidemiological, social and human sciences

2, Improving quality of life for patients and carers in all the situations they face throughout the development of the disease. Action and activity includes:

2.1, Improving access to diagnosis and ensuring a continuous chain of care:

- developing and implementing a framework for initial diagnosis and the follow-up
- experimenting with new payment terms for health professionals
- developing an Alzheimer's information card for patients in case of emergency situations
- creating new local memory centers in areas where there are none
- strengthening the most active memory centers
- monitoring adverse drug reactions

- improving correct use of drug: in 2008 18% of Alzheimer patients were prescribed with antipsychotic drugs which is far too high as a percentage

2.2, Improving support and respite for carers

Developing and diversifying respite care services:

- creating new places
- evaluating existing facilities
- drafting specifications for a therapeutic dimension in all structures
- drafting a guide for respite centers
- experimenting with innovative respite solutions, including for example holiday stays, cultural and artistic activities, sensory stimulation

Strengthening caregivers' rights and training

- 2 days training program for carers to help them cope with the disease
- Supporting them in returning to work
- Improving health monitoring for family caregivers

2.3, Strengthening coordination between all actors involved

One of most innovative measures of the plan is considered to be the integrated access points (« MAIA - maisons pour l'autonomie et l'intégration des malades d'Alzheimer » - houses for autonomy and integration of people with Alzheimer's disease). There are currently 17 trials of this new concept, which aim to integrate social and health care services for the benefit of patients, and provide simple personalised access to these services.

2.4, Enabling patients and their families to choose support at home. Families and patients have clearly expressed their preference for staying at home as long as possible. In order to facilitate this:

- reinforcing home support in the form of specialised professionals
- improving home-support using new technologies: national and European calls for research project are targeting home automation and ICT
- improving residential care which remains necessary in a number of cases
- creating specific units for patients with behavioral problems within nursing homes
- creating specialised cognitive behavioral units within rehabilitation services
- setting up residential services for young patients.

2.5, Developing skill sets and specific training for all care professionals:

- New competences: case-managers and gerontology assistants
- Training for occupational therapists and psychometricians
- Training for all the care workforce

3, Mobilising around a key social issue

3.1, Providing information and awareness among the general public

3.2, Promoting an ethical debate and approach: a national centre for ethics has been set up in Reims. This centre will organise conferences with patient representation and discuss issues such as technology, for example GPS bracelets.

3.3, Keeping patients and their families up to date on clinical trials

Ms Lustman concluded her presentation by affirming the importance of tackling dementia at the European level and ensuring it remained at the heart of the European agenda. She explained that Nicolas Sarkozy had taken the fight against Alzheimer's disease to the European level. This was important she explained, because Europe can foster a better understanding of the disease and there could be greater coordination of research. European collaboration can foster sharing and help develop common principles on the quality of disease management. Europe can also develop an ethic on Alzheimer's management based on its values.

Elaborating on the work of the pan-European conference held in Paris at the end of October 2008, Ms Lustman said that significant progress had been made and mentioned the conference on *Healthy and Dignified Aging* coming up in September in Stockholm under the Swedish Presidency.

Learning from other European Countries

Professor Sube Banerjee, Professor Mental Health and Ageing, Institute of Psychiatry, King's College London

Professor Sube Banerjee was invited to be brief given the late hour and so decided to keep his presentation short, he said we could all learn from our European neighbours, if he were cherry picking his ideal model, he suggested he would steal from:

- Scandinavian Countries for their specialist care homes, which deliver choice, dignity and quality care to individuals in a personalised long term care setting
- Netherlands for their specialist care home physicians
- Italy for their intergenerational support structures and healthy diet
- Germany for their availability of specialists and investigation
- France for their research expenditure and growing investment in support structures and care
- UK, with its plans to increase early diagnosis and treatment from 30% up to 60%+
- The EU for their research and development funds which should be used to fund more dementia research

Global Perspective

Dr John Beard, Director, Department of Ageing and Life Course, World Health Organisation

Dr John Beard said the global dimension to dementia and to demographic change in terms of ageing must not be overlooked. The need for further research on and support for the developing world was critical. Dr Beard said the research community had very limited knowledge of the prevalence of dementia in developing countries for example.

He said that it was necessary to be visionary in our approach to dementia, he thought it would be possible with advances in science and technology to prevent the causes of dementia one day. He highlighted the importance of genetic environmental interactions and future mapping of genotypes which would identify those most at risk. At the present time he stressed all facets of dementia needed to be considered including prevention and detection, treatment and care.

Part 2: Key Themes and Recommendations

This chapter will provide an overview of some of the key themes that emerged from the roundtable discussions following each presentation and some overarching recommendations. It is the intention of this report that these recommendations will be considered and debated further at the forthcoming dementia research summit on the 21st July and in wider public policy debate.

Key Themes

1, Diagnosis

There was a general consensus that dementia should be diagnosed as early as possible, however there was considerable debate on the role of GPs in this process. Several experts commented that GPs did not always have the skills to detect the early signs of dementia. These assertions were strengthened by reference to a report on dementia from the National Audit Office which found that two thirds of GPs did not have sufficient basic post qualification training to help them diagnose and manage dementia.

It was also suggested that many GPs did not necessarily feel it was in the individual's best interest for them to be made aware of their diagnosis, for fear of causing distress. It was however widely expressed that this should not be the case and there needed to be greater levels of awareness regarding people having the right to know their diagnosis, with no diagnosis potentially causing greater harm.

Another barrier to diagnosis was considered to be GPs knowledge of the poor quality advice and support on offer, once the individual received their initial diagnosis. If a diagnosis of dementia could act as a gateway to continuous treatment, advice and support, it was suggested more GPs would be encouraged to make a diagnosis and refer people.

The introduction of memory clinics in every town, announced as a precursor to the strategy, was also generally considered to be a welcome development. The aim behind the initiative is for every GP to be trained to spot the first signs of dementia and will then refer patients to the clinic, where they will be formally diagnosed and be prescribed therapies and/or drugs. However some experts did raise concerns, indicating memory clinics would not be a panacea for early diagnosis and support unless they were embedded in a wider comprehensive strategy. Similarly as the French experience demonstrates, simply by increasing the number of memory clinics does not in itself improve levels of diagnosis, in France there remained significant levels of inertia and reluctance on behalf of GPs to refer patients to the clinics.

The need to improve levels of advice, care, support and treatment following a diagnosis was considered widely to be a significant failure of the current system, it was described by one expert as 'entering a black hole'. It was also highlighted that there needed to be greater support in the pre-diagnosis stage for the individual and their potential carer. Greater thought it was suggested needed to be given to providing effective early interventions, this included improving signposting to information and support services. Broadly the dementia adviser role, as outlined in the National Dementia Strategy, was considered to be a welcome development, particularly with regard to providing a consistent point of contact and support for the individual and their carers.

Widespread ignorance, prejudice and the stigma surrounding dementia were also considered to be a significant barrier to early diagnosis, impacting not only the attitudes and behaviour of the general public, but also some health and social care professionals. Thus a lack of awareness surrounding the condition proved to be a barrier to people seeking help and receiving an accurate diagnosis and referral. Research from the Alzheimer's Society, entitled 'Feeling the Pulse' in 2002 found that on average people wait up to three years before reporting symptoms of dementia to their doctor and when they make it to the surgery they may be met by a mixed response. There

was also some discussion regarding the possible consequences of reframing dementia under a disability model, a few experts thought this would be beneficial with regard to enshrining individuals rights particularly in terms of their treatment in care homes. It was however the general consensus that the specific diseases and conditions of dementia are a medical problem and reframing dementia under a disability model had the potential to cause problems. It was also expressed that the discrimination and ignorance surrounding dementia was compounded by society's widespread prejudices towards older people and of mental health more generally. Dementia has suffered historically from not only poor awareness and understanding, but this had combined with the stigmas attached to both mental illness and old age. With dementia at the intersection of these, it was argued greater public awareness of not only dementia, but also old age and mental health problems was imperative.

With regard to research, it was strongly felt that while the research summit was a welcome development, there needed to be a commitment to a comprehensive strategy on research or a special commission on research established. In terms of diagnosis, it was highlighted that better tools were needed to support and enable the diagnosis of dementia in primary care with research needed to develop robust biomarkers to enable accurate pre-clinical diagnosis. Therefore as disease modifying drugs are developed, they can be prescribed before clinical symptoms and widespread cortical pathology develops to optimise benefits. Ideally this would require the identification of a simple biomarker than can be used as a widespread screening test.

2, Treatment

There was widespread debate regarding clinical trials and the need to develop more effective mechanisms to encourage and promote trials. Several experts commented on the value individuals derive from participating in clinical trials, even noting the placebo effect in several cases. The suggestion of developing a national dementia register for clinical trials was proffered and the possible links that could be made in this respect with the proposed memory clinics. However at the same time, it was acknowledged that the drive to promote and facilitate clinical trials should be balanced with protecting the individual and their carers from any invasion of privacy or any perceived pressure from external organisations.

UK researchers were praised for making the most of limited opportunities. However with only 4 phase 3 clinical trials of new anti-dementia treatments going on worldwide and the average time from turning science into new drugs standing at around 20 years, the pathway for drug approval and development with regard to regulation was also considered to serve as a significant barrier to progress.

There were strong feelings expressed on the low levels of investment in research and development in the UK, with widespread feeling that the currently levels were unsatisfactory. It was stressed that given the demographic changes and the predicted exponential increase in the prevalence of dementia, it made sound economic sense to invest more heavily in research at the present time. There was a strong sense that we should be investing *today* for tomorrow as one expert suggested. Concern was also expressed regarding the Alzheimer bias of most of the current dementia research and the need to redress this balance.

There was also widespread endorsement for more cross-disciplinary working, with the need for new partnerships to be formed for example in neurology and pathology. Similarly there was an acceptance that there needed to be greater collaboration, sharing and transparency between all actors in the dementia field, including academics, pharmaceutical companies, NGOs, voluntary organisations and the health and social care public and private sector.

3, Care

Perhaps one of the strongest themes to emerge from the care debate was surrounding workforce development. There was widespread concern expressed on recruitment, retention, safeguarding and standards. There was a general consensus that many health and social care professionals were not adequately trained and therefore did not have the appropriate

attitude, knowledge or skills set to support people with dementia and their families. This was particularly highlighted to be the case for many social care workers in care homes, who are at the frontline of caring and supporting people with dementia, but are woefully under supported, remunerated and trained. The need to professionalise the social care workforce was expressed by many and it was hoped the adult social care workforce strategy would address some of these issues. The recent report by the All Party Parliamentary Group on Dementia called *'Prepared to Care, Challenging the Dementia Skills Gap'* was also mentioned in this context, the report called for an increased focus on commissioning for quality outcomes in dementia care, stronger regulation and registration of dementia care trainers.

There was also discussion on how to prepare the workforce in certain public and private organisations for their everyday contact with people with dementia. Employees on the front line of service provision for example, employees of transport companies, it was suggested would need some rudimentary training or awareness on how to best communicate, facilitate and serve people with dementia,

The general unsuitability of care homes was also discussed, with disappointment expressed on the postcode lottery for many dementia residents. Several experts specifically mentioned that the vast majority of care homes did not cater for the needs of people with dementia, denying residents choice, dignity, appropriate care and support in their final days. Access to health care was raised to be a significant problem for many people with dementia in care homes, concern was also raised over the use of antipsychotic medication and the susceptibility of people with dementia to abuse. An awareness and distinction of the different conditions and diseases of dementia was also considered to be important in terms of providing tailored care and support.

At part of the Government's *'Putting People First'* agenda, there was also debate regarding the potential for the personalisation agenda to transform care and support services for people with dementia and their families. However there were specific barriers and challenges which merit further consideration in this regard, for example greater evidence on the benefits personalisation can yield for people with dementia and their families and greater assessment of the risks involved.

Greater support and recognition for the role of unpaid carers was mentioned repeatedly. It was suggested greater attention and priority should be given to carers needs, particularly when one considers the demands and exigencies placed upon them on a daily basis. Good advice and support, carers' assessment, short breaks and appropriate financial recognition were all highlighted as important policy priorities.

The need for more social research on developing good guidance, best practice and training resources for people commissioning, developing and delivering services for people with dementia was also discussed. Mechanisms need to be developed so that care services and non-pharmacological therapies with an evidence base of effectiveness are routinely implemented in clinical and care practice. It was also suggested we need to encourage innovation of care services and non-drug treatments, with embedded approaches to develop robust evidence and then implement successful innovation.

Recommendations

These recommendations are formed from the roundtable discussions and are intended to stimulate debate and inform further discussion ahead of the dementia research summit on the 21st July.

With regard to research:

1, A comprehensive and visionary research strategy – The overarching message which emerged from the expert roundtable discussion was the pressing need to develop this agenda and build a comprehensive research strategy which sets out a roadmap for the next 5 years.

2, Greater investment in research - There needs to be a comprehensive plan to ensure the allocation of research expenditure to dementia receives the same investment as other major diseases such as cancer and heart disease. There have been significant scientific advances in dementia research in the past 25 years and it is imperative the UK builds on this success and invests to be at the forefront of research and development.

3, Creation of a dementia research environment – A research environment is cultivated which attracts, develops and retains the very best scientists. The UK needs to attract new teams and attract young researchers from a range of disciplines to reinforce and develop the research base. Continued support for young researchers in established academic departments is also fundamental.

4, Cross-cutting and interdisciplinary research at the UK and EU level . Co-ordinating collaboration on dementia would offer substantial benefits, including greater coherence and synergy in research and understanding, the opportunity for developing new comparative methodologies and databases, standardised instruments and the harmonisation of data.

5, Joint engagement across the public, private and voluntary sector – There needs to be joint engagement by Government, the research community, charities, pharmaceutical companies and people with dementia and those who care for them.

6, Recruitment for clinical trials - Recruitment for clinical trials is challenging for any disease but is particularly so for Alzheimer's disease and other forms of dementia. The development of a national register which holds information on all current trials taking place and appropriate mechanisms on how to communicate and educate people with dementia and their carers on clinical trials needs to be considered.

7, Demonstrate the value of research to a wider audience . Attention needs to be given to how to demonstrate the value of dementia research and how research can contribute to and improve people's lives with dementia. The public should be convinced of the value of dementia research, with research findings reaching as large an audience as possible.

Wider recommendations

1, Increase awareness and understanding of dementia . It is critical to invest in an awareness raising campaign on dementia to educate and inform professionals and the public. This campaign will also need to address the wider discrimination, prejudice and stigma associated with mental health and older people's issues more generally. How a discourse on dementia develops will be critical for the future care, support and treatment of people with dementia and their carers.

2, Strong clinical leadership across health and social care on dementia . the need for better leadership based on new core competencies is essential to drive up standards in health and social care.

3, Investment and training of the social care workforce . workforce development must be a priority if we are to ensure high standards of care, support and treatment for people with dementia and their families. Skills are needed in advocacy, advice, safeguarding, personalisation, mental capacity and carers support.

4, Care homes - care homes need to be fit for purpose and start adapting and developing to provide the specialist care and support people with dementia need, this should include improving levels of diagnosis within the care home setting, appropriate usage of anti-psychotic drugs , a specialist and trained workforce and increased access to health care.

5, Support for carers ó It is essential that the Dementia Strategy and the National Carers Strategy are linked closely with regards to implementation. If these two Strategies do not work together the outcomes for carers of people with dementia will be considerably weaker. Carers

also need to have a decent income, the ability to continue working, back to work support, health checks and better support from the health service for their own health, better information about housing and their rights, and better skills and confidence in caring for someone with dementia.

Annex

Useful information

All Party Parliamentary Group on Dementia: *Prepared to Care. Challenging the dementia skills gap*, June 2009
(available from www.alzheimers.org.uk/downloads/APPG_Report_Prepared_to_care.pdf)

Alzheimer's Society: www.alzheimers.org.uk/site

BBC and PSSRU: Care Calculator, 2008
(available from www.bbc.co.uk/radio4/youandyours/careintheuk/calculator.shtml)

French Alzheimer's Plan References: *Alzheimer Plan 2008-2012*
(available from www.plan-alzheimer.gouv.fr)

HM Treasury: Cooksey Review, *A review of UK health research funding*
(available from www.hm-treasury.gov.uk/cooksey_review_index.htm)

National Audit Office: *Improving services and support for people with dementia*, July 2007
(available from www.nao.org.uk/publications/0607/support_for_people_with_dement.aspx)

National Institute for Health and Clinical Excellence: *Dementia: Supporting people with dementia and their carers in health and social care* (available from www.nice.org.uk/guidance/cg42)

National Institute for Health and Clinical Excellence: *Dementia: Supporting people with dementia and their carers in health and social care* (available from www.nice.org.uk/guidance/cg42)

Open University and the University of Bristol: *The Last Refuge 'Revisited'*, 2005-2007
(available from: www.open.ac.uk/hsc/research/research-projects/the-last-refuge-revisited/the-last-refuge-revisited.php)



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