



# Consumer Involvement in Dementia Care Research, Policy and Program Evaluation

Report on  
Alzheimer's Australia Research Ltd  
Travelling Scholarship

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Society is recognising that people with dementia have worthwhile opinions on their care despite living with cognitive disabilities. In both the USA and the UK, independent organisations and governments are developing structures and processes to accommodate a more active role for people with dementia. The societal ethos of involving people in decisions about the care they receive is continuing to gain ground. Investigations summarised here pointed to some issues yet to be resolved, such as representativeness, the empowerment of marginalised cultural groups and cost-benefit implications when resources are scarce. The issues are complex; inevitably, it has not been possible to cover all aspects fully in this paper. Nevertheless, the activities reported here have provided valuable lessons for Australian practice.

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**CONTENTS**

<b>BACKGROUND.....</b>	<b>4</b>
Definition of consumer	4
<b>AIMS.....</b>	<b>5</b>
<b>METHODOLOGY.....</b>	<b>6</b>
Interviews in the USA and UK	6
Conference	6
Literature searching	6
<b>RESULTS .....</b>	<b>7</b>
Prevalence of dementia in the USA and UK	7
<b>NOTES ON USA EXPERIENCES .....</b>	<b>9</b>
Historical context to consumer involvement in the USA	9
US Surgeon General’s Report on Mental Health	9
Public involvement in research at a national level	10
Californian support for caregivers	10
Research into barriers and facilitators for consumer involvement	11
Involvement of people with dementia in local chapters of Alzheimer’s Association USA	13
National advisory board of people with early dementia	13
Conference for, and organised by, people with early dementia	14
Town Hall Meetings	15
Volunteering or paid roles	16
<b>NOTES ON UK EXPERIENCES .....</b>	<b>17</b>
Consumer involvement in the National Health Service	17
Consumer involvement in guidance and guidelines	17
<b>INVOLVE</b>	18
The Involve People with Dementia Project	19
The UK dementia initiative	20
Involving people with dementia in education and training of dementia care workers	21
Canvassing opinions at Dementia Cafés	21
Dementia Services Development Centre Stirling	21
London Centre for Dementia Care	22
Alzheimer’s Society UK and consumer involvement – QRD Consumer Network	22
Alzheimer’s Research Trust	23
The James Lind Alliance	23
The Scottish Dementia Working Group	23
<b>DISCUSSION .....</b>	<b>25</b>
Lessons for future evaluation of dementia care in Australia	26
<b>CONCLUSION.....</b>	<b>28</b>
<b>ADDENDUM: ALZHEIMER’S AUSTRALIA AND CONSUMER ACTIVITIES .....</b>	<b>30</b>
<b>REFERENCES .....</b>	<b>31</b>
<b>APPENDIX 1.....</b>	<b>34</b>

## Background

### Definition of consumer

The term ‘consumer’ is not universally accepted in health circles, having been borrowed from business/economics, and also being used in legal terms regarding rights in transactions. A consumer is someone who acquires goods or services for direct use; the word perhaps implies a different power relationship with the health professional providing treatment than does the word ‘patient’.

‘Health consumer’, ‘health care consumer’ or ‘client’ are other terms used for a patient, usually by governmental agencies, insurance companies, and/or patient groups, some of whom may object to some implications of the word ‘patient’.

Horey (2007), identified consumer involvement, public involvement, consumer engagement, and patient participation as common terms in sociology. In the context of caring for people with dementia, the word ‘consumer’ often has an ambiguous meaning, referring either to the person with dementia, his or her carer, or both. Consumer and carer are definitely not synonymous. In the psychological literature, the ‘care dyad’ is referred to when considering the complex inter-dependencies of carer and care recipient; the two people are considered to have intertwined as well as separate needs.

More recent terminology has returned to the simple term ‘people’ for those involved in interactions with health professionals and the health system.

NHS Research defines consumers as:

- ?? Patients
- ?? Carers
- ?? Long-term users of services
- ?? Organisations representing consumers’ interests
- ?? Members of the public who are the potential recipients of health promotion
- ?? Groups asking for research because they believe they have been exposed to potentially harmful circumstances, products, or services (Invo, 2000).

*We are all potential consumers of health and social services. However, consumers who get involved in R&D and do not have other, ‘professional’ roles (doctor, researcher etc.), have a distinct and complementary role to play in the R&D process. By ‘consumer involvement’ in R&D we mean an active partnership between consumers and researchers in the research process, rather than the use of consumers as the ‘subjects’ of research. Many people describe consumer involvement in R&D as doing research with consumers rather than to, about, or for consumers (Invo, 2000).*

In this paper ‘consumers’ means people living with dementia and their family carers, but some of the discussion of consumers refers to people with other health conditions and their unpaid carers as well. The above definition from Invo (2000) generally encompasses all types of consumers discussed here. The terms carer and caregiver are used interchangeably depending on the country of origin. Both refer to people who are providing unpaid care for people with a disability or impairment.

## Aims

This paper is a summary of the results of a study tour funded by Alzheimer's Australia Research Ltd and undertaken by the author in November and December 2007. The questions to be explored in discussions paid for by the study tour included:

- ?? How can we involve people with dementia in evaluation of their care?
- ?? How can we involve carers in evaluation of dementia programs?
- ?? What are good strategies for involving consumers in the development of services for people with dementia?

The specific aims of the study tour were to:

- ?? Learn about consumer involvement in dementia care evaluation;
- ?? Exchange information about evaluation of dementia care;
- ?? Attend seminars on dementia and care-giving;
- ?? Discuss quality of life issues and dementia care-giving with experts; and
- ?? Further links with overseas experts on dementia.

In the time available, visits were made to a selected number of individuals and organisations in the USA and UK. It was only possible to scratch the surface of information on consumer involvement in the two countries. This summary notes some key activities of the Family Caregiver Alliance in California, USA, which provides a wide range of services for people with dementia and their carers. The Alzheimer's Association USA (Los Angeles and Chicago), also provided good insight into how consumers are changing their role. In the UK, time spent with Alzheimer's Society and Alzheimer's Scotland provided insight into roles for consumers in research grant allocation and policy development. The National Health Service has strong consumer input, at a number of levels, into service development, research, policy, and program evaluation. Examples of current consumer involvement activities are summarised below. Other organisations and individuals with an interest in dementia were also contacted to find out how consumers were involved in services, research, or evaluation.

## **Methodology**

### **Interviews in the USA and UK**

A series of semi-structured and unstructured interviews were undertaken in the United States (California and Illinois) and the United Kingdom (England and Scotland). A snowballing approach was used as each interviewee suggested other key contacts; these were followed up either in-person or by telephone/email. However, while the questions outlined in the aims above seemed straightforward, the answers were complex and inevitably it was only possible in the time available to gain a partial view of the different approaches taken to involving consumers in research, policy, and program evaluation. A full list of interviewees/contacts is provided in Appendix 1.

### **Conference**

The 40<sup>th</sup> conference of the Gerontological Society of America was attended and a poster presentation was made on community care for people with dementia. Over 5000 people attended the conference, which generated 549 symposia on ageing-related topics, including numerous symposia on dementia care research and evaluation. Information on dementia care was gathered wherever possible.

### **Literature searching**

The grey and academic literature was searched using key words, including 'consumer involvement', 'consumer participation', 'dementia', 'carers', 'caregivers'. Medline 1996–2007 was searched using consumer involvement or consumer participation, limited to human and English language. A total of 5393 articles were found, 351 of which were published in 2007. The literature was used selectively to supplement and expand on interview findings and to inform discussions undertaken with organisations. A narrative summary of some of the literature is provided below.

## Results

### Prevalence of dementia in the USA and UK

The USA and UK have much larger populations than Australia, so it was informative to see the volume of services and structures in place to manage greater numbers of people with dementia. The USA has a total population of over 300 million, and approximately 5.1 million had Alzheimer's disease in 2007 (Alzheimer's Association, 2007). This includes 4.9 million people aged 65 years and older, and at least 200,000 individuals younger than 65 with early-onset Alzheimer's (and 300,000 people younger than 65 with dementia other than Alzheimer's). Table 1 provides a brief summary of dementia prevalence by age in the USA.

**Table 1: Prevalence of Alzheimer's disease in the United States of America**

Age group	Percent (%)with Alzheimer's disease	Estimated number of people in the USA
65-74	2	300,000
75-84	19	2.4 million
85+	42	2.2 million

*Source: Alzheimer's Association, 2007.*

In absolute numbers, California has the most people with Alzheimer's disease over 65 years of age. In 2000, California had an estimated 440,000, Florida had 360,000, and New York had 330,000 people with Alzheimer's (Alzheimer's Association, 2007). Approximately 10 million Americans care for a person with dementia; this figure is about 29 per cent of all carers of people aged 60 and over. In California alone, it was estimated in 2005 that there were over one million carers who provided over 800 hours of care each per year for people with dementia.

The total population of the state of California in 2007 was approximately 37 million. In California the four largest cities are Los Angeles (4 million), San Diego (1.2 million), San Jose (900,000), and San Francisco (800,000). Eleven per cent of the population are over 65 years of age, compared with 12 per cent over 65 years for the whole USA.

By contrast the UK has a total population of 61 million, and it is estimated that about 684,000 people have dementia in the UK. About 20 per cent of people over 80 have dementia (Knapp & Prince, 2007). Estimates suggest that 63% of people with dementia in the UK live in the community and 37% live in residential care. About 18,000 people with dementia are under 65 years. Table 2 provides a brief picture of dementia prevalence by age for the UK.

**Table 2: Prevalence of Alzheimer's disease in the United Kingdom**

<b>Age (years)</b>	<b>Female (%)</b>	<b>Male (%)</b>	<b>Total (%)</b>
65-69	1	1.5	1.3
70-74	2.4	3.1	2.9
75-79	6.5	5.1	5.9
80-84	13.3	10.2	12.2
85-89	22.2	16.7	20.3
90-94	29.6	27.5	28.6
95+	34.4	30.0	32.5

*Source: Knapp & Prince, 2007*

## Notes on USA experiences

### Historical context to consumer involvement in the USA

In the USA the consumer movement had its roots in 1970s protests by former patients of mental hospitals. This so called 'consumer/survivor movement' was one result of a societal change towards empowerment of people in what previously would have been an authoritarian, hierarchical system of health care provision.

Early publications by consumers, such as *On our Own* by Judi Chamberlain (1970), meant that people were able to read what it was like in the mental health system. This book spurred many people on to become active in the consumer movement. In the 1960s the 'mental patients liberation movement' began advocating for self-determination and basic rights. By 1978 the President's Commission on Mental Health stated that groups of people with mental health problems were being formed all over the United States.

Most of these groups were under-populated by racial and ethnic minorities, and this discrepancy apparently continues today.

Since the 1970s, many consumer groups have espoused self-help as well as advocacy. Self-help groups now have a number of models depending on the amount of professional involvement. The focus of consumer groups varies, with some united on the basis of diagnosis, such as the Alzheimer's Association, and others based more broadly. Some programs are entirely run by consumers.

Ronald Reagan's announcement in 1994 that he was diagnosed with Alzheimer's disease had a big impact on the media attention given to Alzheimer's disease and caring issues in the United States. Further development of consumer awareness came in 2000 when the *Older Americans Act* amendment created the National Family Caregiver Support Program. Funds from this legislation come through the Departments of Aging to local Area Agencies on Aging.

More recently, another big impact on the role of consumers in the USA has been the Internet, which has greatly expanded caregivers' access to knowledge and helped to reduce their isolation. And finally, the generational changes associated with ageing baby boomers who have moved into care-giving roles for parents and spouses have meant that care-giving is changing, with a generational shift in attitudes to support systems, and in the extent to which consumers want to have a say in what should be provided (California Department of Mental Health, 2005).

In summary, the historical context illustrated growing community awareness of consumers and their wish to take a more active role in health care.

### US Surgeon General's Report on Mental Health

The consumer movement spearheaded the view that having a mental or cognitive disability does not prevent people from having a say in their health care. The US Surgeon General's Report on Mental Health documented an impressive list of achievements of the consumer movement in mental health.

Included among the achievements listed were:

1. Proliferation of self-help groups: all 50 states and the District of Columbia have 235 different mental health consumer organisations.
2. Mental health planning councils: by law, planning councils are required to have membership from consumers and families. Having a planning council is required for receipt of federal block grant funds for mental health services.

3. Offices of consumer affairs: in many state health authorities the offices are staffed by consumers to support consumer empowerment and self-help in their states.
4. Consumer research agenda: the National Institute of Mental Health is developing a systematic means of including public participants in the initial review of grant applications in the areas of clinical treatment and services research.

## **Public involvement in research at a national level**

Apart from grassroots involvement in health care, a number of opportunities for consumers to be involved in research in the USA exist. There appears to be strong government support for consumer involvement on advisory boards of government-funded research. Up to one-third of advisory council members can be from the general public, although in practice this proportion may not always be achieved. Public representatives help with priority-setting, and are involved in second-layer review (the first layer being peer review of scientific methodology).

As is often the case, it is difficult to find enough people willing to sit on such boards, particularly from a wide enough spectrum to cover the diversity of society (National Institute of Health, 1998). Therefore, while there is a societal view that involvement is important, in reality it is often difficult to recruit people willing to spend the time required for such a commitment.

## **Californian support for caregivers**

According to the Family Caregiver Alliance, California is one of the better states for provision of support for caregivers. The Alliance supports a range of carers, but 75 per cent are carers of people with dementia. The majority of caregivers are women caring for a spouse or a parent with dementia, but today's caregivers are more likely to be in the workforce with children at home, and to use the Internet for information, support and resources. In 2004, half of all family caregivers being supported by the Family Caregiver Alliance were also employed outside the home.

In California, the Family Caregiver Alliance started from a grassroots effort in 1976, from a town hall meeting of a group of families caring for people with brain-impairing illnesses. At the time there was no local, state, or federal organisation that catered for the needs of caregivers of people with cognitive impairment. The establishment of the Family Survival Project in 1979 provided family support, care planning assistance, respite care, education, and legal consultation to caregivers in the San Francisco Bay area. As a result, a state-wide network of Caregiver Resource Centers was established, and in 1984 the role of the Caregiver Resource Centers was legislated to provide care for caregivers of people with Alzheimer's disease and other cognitive disorders that arise in adulthood.

California was the first state to develop a state-wide network of support for family caregivers. In addition, in 1984, the California Department of Aging established Alzheimer's Day Care Resource Centers, of which there are now 64 throughout the state; and 10 Alzheimer's Disease Research Centers of California were established to provide assessment, research, and assistances for families in need.

In 2007, the Family Caregiver Alliance offered a variety of free and low-cost services for caregivers to provide care at the same time as looking after their own physical and mental health. Their services included:

1. Information and referral: information about care-giving issues, including how to care for someone with dementia; 60 or more fact sheets, plus newsletters, reports, and other publications, available in Spanish and Chinese; referral to community programs such as day care, support groups, and home care respite care.

2. Free family consultation: in-home assessment of caregiver and carer's needs; information about services; long-term care planning; community resource referrals; long-term follow-up and re-assessment every six months.
3. Respite options: short-term respite grants to hire in-home help; long-term respite funding up to \$3600 per year (although there is a two- to three-year waiting list for this service); camp for caring four times a year; and caregivers' retreats twice annually.
4. Legal/financial consultation: free consultation with a local attorney.
5. Education and support: workshops and classes, including dementia behaviours, stress management, care planning, practical care-giving skills and more; in-person and online support groups; short-term counselling.
6. Online services: publications, newsletters, online support groups; Link2care caregiver discussion group, and free access to health and legal experts; bi-monthly e-newsletter, focussing on public policy; e-newsletter for families and caregivers in California.

In this large and diverse organisation, consumers mainly have a consultative role. While caregivers are not represented on the Board of the Family Caregiver Alliance, considerable effort is made to provide them with opportunities to evaluate the services that are available. Since 1999, the Caregiver Resource Centers (CRC) formed an Outcomes Task Force to identify and measure self-reported changes in caregiver behaviour and feelings of competence following CRC interventions.

In 2004, the first state-wide caregiver satisfaction survey was undertaken, with 1355 family caregivers taking part. Caregivers now provide regular input to the Caregiver Resource Centers via a Client Questionnaire on the effectiveness of the services offered and whether they are meeting the needs of users. The survey is distributed every six months to users. Answers are given in a numerical and qualitative survey and the resulting database is analysed regularly by the organisation. The California's Care-giving Resource Centers Outcome Report was first published by the Statewide Resources Consultant in October 2002.

## **Research into barriers and facilitators for consumer involvement**

While there is considerable good will regarding the involvement of consumers in planning, evaluation, and research, the issues of firstly representativeness and secondly difficulty recruiting volunteers continue to be raised in many consumer organisations. To what extent are consumer organisations representative of the needs and preferences of the population as a whole? As with early consumer groups, which under-represented minority ethnic groups, current consumer groups continue to work to maintain diversity in the type of consumers that are willing to be involved and willing to accept support services.

Research into the barriers and facilitators for consumer involvement, and the psychological basis for involvement, can provide some insight into consumer engagement. Some consumers are more willing than others to engage in service development and the type of work required by consumer representatives. Research has considered demographic, psychological, and systemic factors that may influence service use and also involvement in consumer groups. There is a group of people more willing to accept services, know about them, are more aware of the system of services available, and more willing to be involved in volunteering associated with organisational and service development. Demographic, socio-economic, cultural, and psychological factors all contribute to the nature of this group of socially-active carers.

According to the research undertaken by Andrew Scharlach and colleagues, carers who have less *informal* support tend to have greater unmet need for services. In a random sample of carers in California, unmet need was greater among Latino sections of the population of carers, a section of the population who are also under-represented in the consumer movement (Scharlach, personal communication).

Systemic factors that influence service use include the preparedness of primary care practitioners to refer patients to support groups. Patients who are referred tend to use services. Information and referrals provided by the Alzheimer's Association chapters certainly lead to increased use of services (Scharlach et al., 2007). This ties in with the recent evaluation of the ACOVE study — David Reuben, UCLA — whereby patients were referred routinely to the Alzheimer's Association as part of their diagnosis by the primary care physician. In the Northern California and Northern Nevada chapters, referrals are faxed to the Alzheimer's Association, which then follows up with the carer and care-recipient instead of waiting for the family to initiate contact. This demonstration project increased referrals to the Association and also decreased time between diagnosis and receipt of services. Some other chapters offer a home visit as well after the referral (Western and Central Washington State Chapter).

Psychological factors also determine the type of person who is likely to accept services to support them, and who is likely to be involved in advocacy and support groups. Personality has a significant effect on the physical health of spouse-carers, with coping skills and decision-making styles mediating many decisions about care. Hall, Lee, and Hooker (2007) presented work showing that carers with high neuroticism scores perceive caring as more stressful and have high feelings of burden and subsequent negative health outcomes. Extraversion is negatively correlated to depression and anxiety levels — more extraverted carers tend to be less prone to depression and anxiety. Many studies have shown a persistent link between personality and mental and physical health outcomes for carers, to the extent that personality screening may be important to include in health screening for carers. There appear to be no effects of gender or care-recipient disease on the physical health outcomes for carers (Hall et al., 2007).

Perceptions of stress will impact significantly on willingness to be an involved consumer. A recent study found that the more stress a family caregiver experienced — often caused by caregiving-related physical strain, financial hardship, and care-recipient behavioural problems — the more likely was the admission of the care-recipient to residential care (Spillman & Long, 2007). Having a highly stressed carer at baseline increased the probability of admission to residential care by 12 percentage points at 12 months, and 17 percentage points at two-years. The study suggested that reducing caregiver stress was one strategy to avoid or delay the decision to admit the care recipient to residential care (Spillman & Long, 2007).

Decision-making styles can obviously also impact on caring for people with dementia. Narayan et al. (2007) reported on a study of decision-making among wives caring for their husbands with dementia. Three decision-making styles were identified through qualitative analyses. Planners/deliberators used an orderly process of decision-making, finding out information, and weighing up available options. Reluctant decision-makers were aware of the need to make decisions, but did not want to make them or were caught up in ambiguity. Finally, some wife caregivers were caught in the disease/caregiving situation and forced to make immediate decisions because of their situation.

Say et al. (2006) reviewed patients' preferences for involvement in medical decision-making. They found that patients' preferences for involvement in decision-making depended on demographic variables. Younger, better-educated patients and women preferred a more active role in decision-making.

The experience of illness and medical care may also affect preferences for active involvement. There is some evidence that people are happy to take an active role in decision-making early in illnesses, but for more severe illnesses there is less interest in active roles, possibly due to lack of familiarity with the illness.

Decision-making capacity in the person with dementia also influences the extent to which people can participate in evaluation of services and decisions about their own care. Huthwaite et al. (2006) followed people with mild Alzheimer's disease for two years, tracking their decision-making capacity in comparison with healthy older people. They used the Capacity to Consent to Treatment Instrument,

a psychometric measure that tested four core capacity areas: evidencing/communicating choice; appreciating consequences; providing rational reasons; and understanding the treatment situation. At the initial stage, decision-making capacity was already impaired relative to healthy older adults, although simple consent ability in treatment choice was intact early in the disease. Over the two-year period, the people with mild Alzheimer's disease declined substantially on appreciation, reasoning, and understanding, while control performance was stable. Alzheimer's disease patients also showed a decline in their simple consent ability of evidencing choice over the two-year period.

In summary, a number of factors influence whether carers get involved in consumer decision-making. Having supportive services that invite or refer consumers helps to engage them at a number of levels. Younger, better educated women prefer a more active role in decision-making. Stress clearly impedes caring and decision-making, and it is unlikely that stressed carers will want to be involved in policy development, research or evaluation. Decision-making in people with dementia is also impaired by definition quite early in the disease, so carers who are stressed, and people with dementia, will need extra support to be involved in the added work of being an active consumer.

## **Involvement of people with dementia in local chapters of Alzheimer's Association USA**

The Alzheimer's Association in the USA has a long history of advocacy for consumers. In 1995, it conducted a study of consumer responsiveness in state home- and community-based care programs, in order to identify elements in programs that families and care-recipients perceived as particularly responsive to their needs.

Six features were identified as elements that greatly assisted consumers in finding the most appropriate services to meet their care needs:

1. Eligibility criteria: arbitrary age restrictions can prevent people with Alzheimer's disease from entering a program. Assessment of functional ability should include an evaluation of behavioural problems, the need for supervision, and the extent of dementia.
2. Needs assessment: assessment instruments must be sensitive to the cognitive as well as physical impairments associated with dementia.
3. Range of services: there needs to be a range of services available, including carer support, respite programs, adult day care services, reimbursement for supplies, and other non-medical services.
4. Choice of provider: having a choice of providers puts consumers in control of the decisions that affect their lives; this is critical with a disease that will inevitably diminish decision-making abilities.
5. Local decision-making: crucial to the flexibility of the program in meeting consumer needs is the case management agency and the involvement of the family. The individual attention of the case management agency is the key to the program's responsiveness.
6. Consolidated access points: consumers are easily lost in the maze of programs available. A single access point can help bring all the features of the support system together and also link public and private services.

## **National advisory board of people with early dementia**

One of the newer aspects of the Alzheimer's Association USA is the active involvement of people with early dementia in the Association's planning and advocacy. Based in Chicago, there is a national advisory group of fourteen people with early dementia – carers are not included in meetings, although they may support members' travelling needs. Eleven out of the fourteen people are under 65 years of age, which reflects the characteristics of people willing to participate rather than any conscious decision to choose younger people for the Board. People are recruited via the 78 state chapters, with

volunteers responding to a general invitation to join the Board. The chapters each identify and nominate people to serve on the Board. The choice of Board members is based on a goal of broad diversity of membership without any specific stratification.

Participation involves monthly conference calls and two in-person meetings. Membership is for one year; a new Board is then elected. Currently (December 2007) in Chicago, the Association is creating a new position of Director of Early-Stage Activities, and it is anticipated that the person filling this position will develop these activities further. Members do not receive any training, and one of the challenges in managing the group may be monitoring the expectations of the members in terms of outcomes of their decisions (personal communication, Alzheimer's Association Chicago).

In 2007, a total of 25 people responded to the invitation to be part of the advisory board, and fourteen were selected for the positions. Most people who responded to the invitation were younger onset people, despite younger people with dementia only forming two per cent of the total number of people with Alzheimer's disease. The response confirms research summarised above — that younger, better educated people are more interested in being involved.

Advisory Board Members serve as spokespeople for the Association, and their roles include:

- ?? Media liaison.
- ?? Advocates to state/federal legislature activities.
- ?? Advisors on a host of different projects being undertaken by the Alzheimer's Association.
- ?? Internal assessment of projects that would benefit from their perspectives.
- ?? Annual conference planning and appearance; three people with early dementia sit on the planning committee.

## **Conference for, and organised by, people with early dementia**

The Los Angeles chapter of the Alzheimer's Association recently held a conference for people with early dementia. The conference, called 'Living our lives, planning our futures', was held on October 27, 2007, and was organised by two people with dementia in their 50s and 60s (two members of the National Advisory Board). Pioneered in the New York chapter, the forum was indicative of the move towards Alzheimer's Association chapters providing more services for people with dementia rather than the emphasis being on support for carers. A committee of advocates helped the two men plan the conference.

According to an article in the LA Times, the forum had a marked effect on advocates and professionals who attended:

*For many of the advocates and experts, the organizing sessions marked the first time they'd listened to people with Alzheimer's instead of speaking for them. Elyse Salend, a specialist on aging who works for the grant-giving Archstone Foundation, left one meeting thinking, "That could be me". Mary Engel, 2007*

In discussions for this study tour, the new visibility for the person living with dementia in the Alzheimer's Association was attributed to a number of factors: societal shift in perception of the disease; the increasing popularity of anti-dementia drugs, which delay the decline associated with the disease; earlier diagnosis; and a generational shift as 'baby boomers' are diagnosed and have a different attitude to health care compared with earlier generations.

## Town Hall Meetings

Related to the early dementia forum in Los Angeles, all national chapters are currently (December 2007) holding ‘Town Hall meetings’ in which public advertisements invite all people with dementia and their carers to a face-to-face meeting to tell the Alzheimer’s Association what they can do to help further. Meetings are facilitated by co-hosts from the local chapter. A brief introduction from a panel of experts and two people with early-stage dementia sets the scene for a general structured discussion around the following themes:

1. Interactions with the medical community (diagnosis; available treatments/medicines; participation in research).
2. Changes in daily life (loss of independence; coping with changes in function; changes in roles and relationships (personal or professional); safety issues (driving, wandering, home-safety).
3. Engaging community resources (availability and access; care and support services; meaningful activities; and social opportunities).
4. Engaging the fight against the disease (meaningful advocacy activities; involvement in public awareness activities).

As well, for those people who are unable to attend meetings, the Alzheimer’s Association website includes a Town Hall “Share your opinion” page. The website ([www.alz.org](http://www.alz.org)) enables people to comment on a range of topics, as shown in Table 3 below.

**Table 3: Questions used to encourage consumers to share their opinions about dementia care by Alzheimer’s Association USA, in town hall meetings and website discussion pages**

Share your opinion	Questions
Diagnosis Please describe your diagnosis experience	If you had difficulty getting a diagnosis from your doctor, what did you do? Is there anything your family could have done to improve your diagnosis experience? What could health care professionals have done differently to improve your diagnosis experience?
Medications Please describe your experience with medications	What do you think can be done to improve access to treatments? What do you think your family could do to help you get the best medications? What can professionals do to help you get the best medications?
Research Participation Please describe your interest in participating in research	What can your family do to help you participate in research or a clinical trial? What can professionals do to help you participate in research or a clinical trial?
Independence Please describe how you cope with changes in your independence and function	What coping strategies have worked for you? How can your family help you cope? What can professionals do to help you cope and manage the changes in your function?
Roles and relationships Please describe your experiences with changing relationships	How have you dealt with the changes in your personal and professional relationships and roles? Is there anything your family could do to help you cope with changing roles? Are there ways professionals could help you cope better with changing relationships?

Share your opinion	Questions
<p><b>Safety</b> Please describe any concerns you have about your safety, such as driving, getting lost or living in your home</p>	<p>What are you doing to keep yourself safe? What can your family do to help you remain safe? What can professionals do to help you remain safe?</p>
<p><b>Care and Support</b> Please describe your experiences getting local care and support services</p>	<p>What care and support services do you wish were available in your community? What can your family do to help you access care and support services? What can professionals do to provide you with care and support services?</p>
<p><b>Socializing</b> Please describe your experience with activities and social opportunities in your community</p>	<p>What activities and social opportunities do you wish you had in your community? What can your family do to help you get more involved with activities in your community? What can professionals do to provide activities and social opportunities in your community?</p>
<p><b>Advocacy</b></p>	<p>In your experience, what is the general public attitude about Alzheimer's disease? Have you been involved in raising public awareness about AD? What barriers did you face to do this? What benefit has it had for you? Are you more politically active than before your diagnosis of Alzheimer's disease? If someone running for President was here right now, what would you tell him/her about living with Alzheimer's disease and what they should do?</p>

## Volunteering or paid roles

In mental health spheres, the notion of continuing to provide a worthwhile working role, while managing a mental health disorder, is slowly gaining acceptance, and paid workers as well as volunteers play a valuable role in advocacy. Consumers are hired at all levels, from case manager aides to managers in national advocacy organisations (USA Department of Health and Human Services, 1999).

While the Alzheimer's Associations in the USA have embraced the notion of including people with early dementia on advisory boards, in organising conferences, and in working in voluntary capacities, they have not moved to employing people with dementia in paid positions. The notion of payment for services may be an issue for the future as people in Australia start to delay retirement. It was noted that paying people with dementia in the USA would affect any benefits being paid to them.

## Notes on UK experiences

### Consumer involvement in the National Health Service

The principle of user involvement in health services has, for some time, been accepted as a feature of service development in the UK. 'Health of the Nation' (1992) sets out the principle that everyone has a duty to consult with users and their carers fully in drawing up and maintaining community care plans. In the National Health Service, people can be involved in research, policy, and program evaluation, as individuals or as members of an organised service user group or a charity working on their behalf (Oliver et al., 2004). Oliver et al. pointed out that consumers can be consulted about research needs, or invited to work collaboratively with researchers or research funders. Occasionally it is the service users who take the initiative and either they lead the research themselves, or more usually researchers or research funders respond to calls for research. Involvement occurs in many settings, such as interviews, focus groups, town meetings, committee meetings, or as research participants.

The expectation is that informal carers should be involved in the planning, implementation, and review of services. Most is learnt when service users are involved collaboratively, and they play a part in planning, evaluating, and reporting their involvement. Carr (2004) indicated that "there has been a move away from the idea of just consulting people about agency-led proposals to the notion of developing services in active partnership with those who use them".

There are statutory expectations of consumer involvement in the UK with substantive rights attached (Roulstone et al., 2007). The Practice Guidance that accompanied the Carers and Disabled Children Act (2000), saw carers and care recipients as partners, and required professionals to listen to the needs of carers during assessment processes (Roulstone et al., 2007).

However, according to Roulstone et al. (2007), progress towards increasing carer participation in service planning and review is limited. The majority of local authorities have carer strategy groups or forums in place, although their degree of activity and effectiveness varies. Roulstone et al. (2007) pointed out that the degree to which 'hidden' carers or marginalised carers were participating was probably an area of weakness for most organisations.

Again, the issue of the extent to which active carers are representative of the range of carers in the community has been raised. In the survey reported in Roulstone et al. (2007), 34/109 (31%) of the organisations surveyed had written policies to address the needs of marginalised carers. Most participation efforts had been concentrated on the carers of those with learning difficulties and mental health problems, while carers of people with dementia received less attention.

### Consumer involvement in guidance and guidelines

The National Institute for Health and Clinical Excellence (NICE) is an independent organisation responsible for providing guidance and guidelines on the promotion of good health in three areas: public health; health technologies; and clinical practice. Guidance is developed using the best available evidence in a transparent process that involves all stakeholders: the wider health community, including health professionals; NHS staff; industry; academia; and patients and carers. NICE develops guidelines for the best treatment according to best available evidence, and is committed to involving patients and carers in the development of the guidelines.

Consumers have the opportunity to be involved in guideline development in three ways:

1. Stakeholder involvement: national organisations representing patients and carers can register a stakeholder interest which provides opportunities to comment on draft scopes, nominate

patient/carer members to the Guideline Development Group, submit evidence to the Guideline Development Group, and comment on final drafts of the guideline.

2. Guideline Development Group (GDG) membership: all NICE GDGs are expected to include at least two patient/carer members. Patient carer members may be direct recipients of services, carers, or employees of organisations representing patients, carers, and service users.
3. Information for the Public: the recommendations in NICE guidelines are explained in a version written for patients, carers and the public (Jarrett et al., 2004).

The topics for guidelines are chosen through advice from a number of sources, including from within NICE itself; the National Horizon Scanning Centre; the Department of Health's national clinical directors and policy teams; clinical and public health professionals; patients and carers; and the general public. A guidance document on dementia was published in 2006.

There is also a Citizens' Council associated with NICE. The Citizens' Council consists of 30 members of the general public who meet two to three times a year for three days on each occasion to hear expert information on controversial topics and to discuss the issues raised. The council is there to help NICE guidance documents to reflect broad social values of the time.

While the guidelines on health care are produced with great care and attention to consumer involvement, the implementation of guides may be inconsistent across health areas in the UK. The ERNIE database is a source of information about the uptake and implementation of NICE guidelines. In 2004, Linda Jarrett and the Patient Involvement Unit of NICE published an evaluation of the first patient/carer membership of the NICE guideline development groups, to describe how consumers viewed the whole process of engagement.

The evaluation reported on patient and carer experiences of being members of the Guideline Development Group; identified good practice; highlighted problems in the procedures adopted; and made recommendations for future development. They found that, overall, patients/carers and chairs of groups were positive about consumer involvement, but they also identified five areas where consumer involvement could be improved.

Problems that they identified included:

1. Information, training, and support provision: there was less training and support than consumers would have liked.
2. Lack of involvement in defining the scope, and dissatisfaction with the scope: consumers wanted to be involved in defining the scope of their role.
3. Organisation and conduct of meetings: some meetings could have been conducted more sensitively to account for consumer expertise.
4. Consumer research skills: consumers sometimes felt a lack of research skills.
5. Access to information on other consumer views: sometimes there was not enough feedback or communication about other consumer views.

## INVOLVE

INVOLVE is an advisory group on public involvement in research and development in the UK Department of Health (invo.org.uk). It was established in 1996 as 'Consumers in NHS research'. In 2001, it widened its role to cover other areas in the Department of Health through its policy research program, including public health and social care. The group has about 20 members, and meets four times a year. Members are a broad mix of people, including users of health and social care services, carers, representatives of voluntary organisations, health and social service managers, and researchers. All are appointed by the Director of Research and Development at the Department of Health.

The outcome of greater consumer involvement is expected to be research that is more relevant to people's concerns and needs; research that is more reliable; and research that is more likely to be used, although there is little published evidence of any of these outcomes.

INVOLVE's aims are to ensure that public involvement improves the way that:

- ?? *Decisions are made about what should be a priority for research*
- ?? *Research is commissioned (chosen and funded).*
- ?? *Research is carried out*
- ?? *Research findings are communicated*

These aims are achieved through the following objectives:

- ?? *To develop key alliances and partnerships to promote greater public involvement in research*
- ?? *To support members of the public to play an active role in research*
- ?? *To monitor and assess the effects of public involvement in NHS, public health and social care research (Involve, 2007)*

A report by Christine Farrell (2004) summarised the research evidence that underpins involving the public in the NHS planning and service delivery. According to her evidence, involvement increases patient satisfaction. Benefits noted in Farrell (2004) also included greater confidence, less anxiety, better understanding of personal needs, improved trust, and better relationships with health professionals, at least among the consumers who were involved.

## **The Involve People with Dementia Project**

From 2002 to 2005, the Department of Health in the UK funded a project to explore how people with dementia can be involved in service planning and development. The result was an excellent report by Cantley, Woodhouse, and Smith (2005), which summarised the results of the project. In their report, they provided the following reasons for involving people with dementia in service planning and development:

1. Such involvement has lagged behind similar models with other groups of health service users and needs to be brought into line with practice for other users.
2. When people with dementia are enabled to communicate, they have important things to say about how to care for them.
3. Not involving people with dementia is excluding them from society.

Involvement can operate at a number of levels, from influencing individual services to changing attitudes at a national or international level. Some involvement activities are more empowering for people with dementia than others. Nevertheless, there is a wide array of approaches available that can be suitable for use with people living with dementia. Such approaches as detailed in the Cantley et al. (2005) report can include individual consultation, group consultation, participation, and collective action. A number of methods are suitable for each of these approaches.

The report provided some key tasks for managers, and key tasks in practice. It is not possible to summarise all the key tasks here, but the following are some pertinent examples. Key tasks for managers might include taking steps to include the heterogeneity of voices of people with dementia, and changing the attitudes of staff to encourage them to view people with dementia as valued contributors to their service development. Key tasks for practice might include creating opportunities for small group discussions in any large meetings; reporting back to all involved in activities to let

them know what happened as a result of their participation, and planning to move people on to other activities when involvement is no longer appropriate for them.

## The UK dementia initiative

A new dementia strategy is being developed in the UK, starting from August 2007, prompted by two major reports, the Dementia UK report (Knapp & Prince, 2007), and the National Audit Office's report on dementia care (National Audit Office, 2007). The strategy is being written by Sube Banerjee (Institute of Psychiatry, London) and Jenny Owen (Department of Health), in consultation with a working group and program board in the UK Department of Health. There is also an external reference group, chaired by the CEO of Alzheimer's Society UK, consisting of a main group and three working groups.

Three broad areas are being worked on in the overall strategy:

1. Early diagnosis, which is concentrating on primary care, and care pathways.
2. Awareness, particularly among health professionals, including up-skilling of staff, training.
3. Quality: improving inspection programs for care homes, and improving the experience of the person with dementia.

A draft consultation strategy is likely to be available in April/May 2008, and by October 2008 the strategy will be launched. Unlike Australia, funding for the initiative is not distributed from a central national fund. It is expected that boroughs will implement the recommendations of the strategy from their own unallocated new funds. Each borough will be in control of its own implementation of the strategy, and may prioritise two or three main activities.

As part of the dementia initiative development, a new resource was produced on strengthening the involvement of people with dementia (Care Services Improvement Partnership, 2007). People with dementia and their carers were involved in its development, and the document is expected to be a key resource in improving dementia care in the UK. The document outlines the advantages of involving people with dementia in services. Key messages are repeated below in Table 4.

**Table 4: Advantages of involving people with dementia in service evaluation and policy development (Care Services Improvement Partnership, 2007)**

<p>For people with dementia</p> <p>As a person using a service you have a right to be involved:</p> <ul style="list-style-type: none"> <li>✍ You have a personal perspective about dementia that no-one else can provide.</li> <li>✍ Involvement can increase confidence and self-esteem.</li> <li>✍ It can provide a role and occupation and contribute to a better quality of life.</li> <li>✍ You can provide positive examples of living with dementia encouraging others to get involved.</li> <li>✍ You will contribute to removing the stigma associated with dementia as well as mental health in general.</li> </ul>
<p>For commissioners</p> <p>Involving people who use a service is a policy requirement:</p> <ul style="list-style-type: none"> <li>✍ It can provide evidence where services are no longer required and how new services should be shaped optimising the value of available resources.</li> <li>✍ Feedback through involvement gathers data for audit and evaluation purposes and feeds into performance assessment frameworks.</li> <li>✍ It ensures fair access to public services and benefits.</li> <li>✍ It ensures equality of treatment and protection.</li> <li>✍ Involvement improves standards and responsiveness.</li> <li>✍ Involvement generates new ideas.</li> </ul>
<p>For practitioners</p>

People who are involved, whether practitioners or those receiving services, feel empowered:

- ☞ Information gathered and acted upon ensures the most relevant services are provided.
- ☞ It meets the personal and social needs of people using services.
- ☞ It can assist people with dementia and practitioners to develop their potential.
- ☞ It illustrates respect for individuals and their communities.
- ☞ It promotes dignity, individuality, rights, responsibilities, identity, and personal preferences.
- ☞ Involvement promotes trust in services and may guard against abuse.

## **Involving people with dementia in education and training of dementia care workers**

Apart from direct involvement in service development and evaluation, people with dementia are beginning to take part in the development of education and training of the health care staff who will be looking after them. The Bradford Dementia Group are leaders in involving people with dementia in the education and training of dementia care workers through the courses provided at the University of Bradford. All courses for health professionals who work in the NHS have to have patient and public involvement in their development, design, and delivery. This requirement is being addressed through a network (PEPIN) of information sharing, and a higher education dementia network.

A survey of higher education institutions providing modules on dementia and older people with mental health needs found that some were involving carers, but Bradford is one of the few institutions involving people with dementia as well. Bradford has a person with early vascular dementia on the course management team, which is a team of stakeholders that meet twice a year to advise on courses and to look at course evaluations. The person with dementia is met with separately before the meeting to brief her on the content of the meeting.

## **Canvassing opinions at Dementia Cafés**

Staff from the Bradford Dementia Group have attended dementia cafés to find out what people thought about health services for people with dementia in the area. Semi-structured, informal interviews were undertaken successfully with people attending the cafés. Other UK dementia workers have also involved people with dementia in the development of dementia cafés. For example, Penny Redwood, Leeds Social Services, evaluated the dementia café DeCaf by sending questionnaires to people with dementia and their carers, conducting face-to-face, semi-structured interviews at the café, and distributing questionnaires to staff as well. These informal approaches are well received by users of the dementia cafés.

## **Dementia Services Development Centre Stirling**

Malcolm Goldsmith, from the Dementia Services Development Centre in Stirling, initiated some work on involving people with dementia in evaluation of services, resulting in the publication of 'Hearing the voice of people with dementia: opportunities and obstacles' (Goldsmith, 1996)<sup>1</sup>. His work pointed the way towards changing the attitudes of health workers to people with dementia.

Kate Allan (2000) extended Malcolm Goldsmith's work, writing about a project in which she explored how residential care staff could encourage service users with dementia to express themselves regarding their view of the help they were receiving. Action research was used to try a wide variety of approaches to fostering better communication. Allan found that organisational factors, such as the general ethos of the organisation, staffing levels, diversity of the people with dementia, routines, and limitations imposed by shifts, were important in modifying the involvement of people with dementia

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<sup>1</sup> Soon to be updated, personal communication Dementia Services Development Centre.

in their care. Staff factors had a big impact on the success of communication with people with dementia. Such staff factors included attitudes and behaviour, self-esteem and confidence, personality factors, relationships with individual service users, variability in the wellbeing of staff, illness, and absence.

Another example of people with dementia being involved in developing services was provided by Bamford and Bruce (2000), who used a group session to ask people with dementia what types of outcomes they were interested in from community care services. It appears that consultation with people with dementia about the care they receive is further developed in residential care services than in community care.

## **London Centre for Dementia Care**

The London Centre for Dementia Care (LCDC) is part of the network of Dementia Services Development Centres and was established in 1998. It is hosted by University College London and provides a range of educational and support services for people interested in dementia care. There is also a specialist library on patient and public involvement in care. The LCDC has a strong volunteer tradition. The LCDC is a collaborative venture between the academic, statutory, and voluntary sectors.

A number of supporters have contributed to its work on a voluntary basis as members of the Steering Group, representing the LCDC at events and attending meetings on the centre's behalf.

The centre's website details a range of activities in which people with dementia can be involved (<http://www.ucl.ac.uk/dementia>).

## **Alzheimer's Society UK and consumer involvement – QRD Consumer Network**

The Alzheimer's Society UK includes among its roles the management of funding for research into dementia cause, cure, and care in the UK. The Society contributes approximately GBP1.6 million in research funding. Currently (September 2007), the society is funding nineteen projects, eight fellowships, and two PhD studentships. The Alzheimer's Society in the UK has an active group of consumers — the Quality Research in Dementia Consumer Network — who set priorities for research, select proposals for funding, monitor ongoing projects, and assist in disseminating the outcomes of research. One hundred and eighty consumers in twelve Alzheimer's Society regions have been recruited to take part in the program, which has been running since 1999. All are volunteers. Consumers are involved in:

- ?? Reviewing grant applications.
- ?? Committees that make funding decisions.
- ?? Steering committees for funded projects.
- ?? Disseminating and implementing research findings.

Consumers undergo training in four modules to support them in their role. The modules cover (i) what research is; (ii) personal development; (iii) critical appraisal skills; and (iv) working collaboratively with 'professionals'. A manual was produced in 2004, and revised in 2007. The approximate cost of maintaining the consumer network was reported to be GBP60,000 per year, of which GBP25,000 is postage costs, as many of the consumers do not yet have access to broadband Internet. The network is expanding under current direction, and is expected to reach 200 consumers with a full-time liaison person to support them in future. A demographic survey in 2004 showed that the consumers' average age was 67, with 60% being female.

Shirley Nurock was the first consumer to be awarded an Alzheimer's Society research grant, in partnership with a researcher.

*On writing up one of the papers for publication there were fundamental differences between Shirley's conclusions and those of the researchers.*

*"Is this what happens when a carer and researchers look at an emotive question from very different perspectives? But why is my perspective any less valid than theirs?"*

*Overall, Shirley felt that her experience of being the first carer to be awarded a grant by the Alzheimer's Society had been very positive and recognised that the dissemination of findings, by an involved consumer, seems to have more impact on audiences than when spoken by a researcher or clinician. (Involve, 2003)*

## Alzheimer's Research Trust

The Alzheimer's Research Trust is a registered charity in the UK that provides ten different types of research support, and is funding grants to a total of GBP3 million for dementia research in 2006 ([www.alzheimers-research.org.uk](http://www.alzheimers-research.org.uk)). Grants are made to applications reviewed by an Expert Referee Panel and Scientific Advisory Board. The Scientific Advisory Board has two lay members, the other members being scientists with expertise in dementia research. The Expert Referee Panel consists of national and international experts in dementia research, but no consumers or 'lay' members.

## The James Lind Alliance

This organisation uses partnerships between consumers and clinicians to improve communication between the two groups.

- ?? The James Lind Alliance (JLA) is about **'tackling treatment uncertainties together'**. Patient organisations and clinician organisations will work together to confront uncertainties about the effects of treatments. JLA Working Partnerships consist of at least one patient organisation and at least one clinician organisation.
- ?? Whenever possible, patients themselves should present their interests and views in JLA Working Partnerships. When they are unable to do so, for example, when suffering from cognitive impairment, the families or other carers of patients, or other non-clinician advocates, may try to represent their interests.
- ?? The clinicians comprising the other half of each JLA Working Partnership must include those who are routinely involved in treating patients with the health problem(s) being considered.

## The Scottish Dementia Working Group

Alzheimer's Scotland is a separate organisation from Alzheimer's Society, which covers England, Wales, and Northern Ireland. Alzheimer's Scotland has branches throughout Scotland, with the head office in Edinburgh. The Scottish Dementia Working Group allowed me to attend one of their regular meetings. This group is based in Glasgow, and meets at the Alzheimer's Scotland office monthly (approximately). It consists of people diagnosed with dementia. Most are men, in their 60s or 70s. They are campaigning for improved services for people with dementia in Scotland.

The national coordinator, Philip Bryers, helps with administration of the meetings. Funding is received from Alzheimer's Scotland and Comic Relief. The annual budget to support the group is approximately GBP60,000, although funding for 2008 was recently increased to GBP90,000, which will allow for more meetings and extension of the group to other towns such as Inverness.

Members speak at conferences, and have been meeting the Scottish Minister regularly in 2007 to discuss development of services. In March 2006, the first UK convention for, and by, people with

dementia was organised by Dementia North, the Scottish Dementia Working Groups and the Living with Dementia team <http://www.alzscot.org/pages/media/ukconvention.html>.

## Discussion

From this brief tour of consumer involvement in the US and UK, it appears that most of the opportunities to be involved in planning research, policy, or program evaluation are for carers rather than for people with dementia. But there are growing opportunities, especially for younger people with early-stage dementia, to be engaged in relatively high profile activities such as service and policy development. Furthermore, research into the differences between proxy perceptions and the perception of the person with dementia is showing that both the carer and the person with dementia have valuable, and sometimes different, points of view on health care.

An early paper outlined the various roles that consumers — not just those with dementia — could adopt in research, policy, and program evaluation. Roles ranged from receiving information or being consulted to planning jointly and having more control or even taking full control of the activity, the implication being that the latter roles were better than the former (Brager & Specht, 1973). More recent interpretations of this ‘ladder’ of roles have emphasised that all levels of participation are valuable. The work summarised here has shown the diversity of ways to involve people with dementia and their carers. Cheston et al. (2000) identified five methods of involving people with dementia in the evaluation of services:

1. Focus groups: these can be used to help people with dementia to discuss the services they receive. However, the facilitator needs to be skilled at helping people with fewer verbal skills to be heard if they are in a mixed group with others more adept at expressing themselves.
2. Questionnaires or structured interviews: for people with mild cognitive impairment, questionnaires administered in-person and concentrating on social aspects of care can be used to communicate either a positive or negative view of the service. More rigid or structured questionnaires are not suitable.
3. Semi-structured interviews: these follow a general series of topics, and allow the person with dementia to raise issues not on the original topic list.
4. Observation: techniques like Dementia Care Mapping can be used in residential settings; observation lasts at least six hours and can be a means of evaluating quality of care as well as giving feedback to staff.
5. Advocacy: this is the more commonly used method of involving people with dementia. Advocates can be legal, professional, family, public, or citizen.

The work reported here has provided examples of people with dementia appearing on advisory boards, with support and training being provided. There were also examples of people with dementia organising high profile events, such as conferences and meetings with the general public, providing a normalising influence on the way dementia is portrayed in the public eye. Carers of people with dementia are making decisions about priorities for dementia research, and having a say in how services are organised and developed.

By comparison, Australian consumer involvement in dementia care research, policy, and program evaluation is well-advanced. Australian health services have been acting on societal expectations of involving consumers in the strategic development of services for some time. The National Standards for Mental Health Services (1996) specified that consumers should be involved in the evaluation of mental health activities. In Victoria, consumer participation in public mental health services has been on the agenda for over ten years, and a recent action plan is aimed at improving consumer participation across all areas of the public mental health service.

Similarly, the Australian Standards for Psychiatric Disability Rehabilitation and Support Services reinforced the involvement of consumers at all stages of planning, implementation, and evaluation of services, and the Third National Mental Health Plan (2003-2008) reinforces the inclusion of consumers in policy, service planning, delivery, and evaluation. The Victorian Department of Human

Services publication *Doing it with us not for us* (2006), provided some objectives that illustrated how involvement can improve the wellbeing of community members. All these activities are very relevant to how people with dementia are involved in health service planning, although, as is the case overseas, there are sometimes parallel but separate mental health and dementia activities.

At a conference in Perth in March 2008,<sup>2</sup> a new guide for health and medical research organisations on how to involve consumers and the community in health and medical research was launched (McKenzie & Hanley, 2007). While none of the examples of participation listed in the document were about dementia care, the models were close enough to provide directions for future developments in dementia care research and program evaluation.

Happell and Roper (2007) identified seven advantages of consumer involvement in research:

1. Research results are likely to be more relevant to positive outcomes for consumers.
2. Consumers use the services so are able to provide a better perspective on appropriate methodologies.
3. Collaborative relationships with consumers are good for academics.
4. More equal relationships will increase the credibility (face validity) of the research.
5. Consumers can become more skilled in research.
6. Consumer involvement may increase recruitment of participants.

Barriers identified included the negative attitude of health professionals when the power relationship is changed to one of a more equal basis. Other impediments included attitudes that people with mental illness are not capable of participating meaningfully. Similar attitudes exist to people with dementia having a say in research. A barrier that may be simpler to overcome is the lack of skills and training of consumers. For example, this has been overcome at the Centre for Mental Health Research (Australian National University), where academic consumer researcher positions have been established, and through the provision of training for consumer researchers in Wollongong.

Another barrier to effective consumer involvement, as noted above, is the degree to which consumers are considered representative of the broader group of consumers. This is an important barrier to overcome, especially when health professionals and research scientists are reluctant to embrace the consumer empowerment model.

Like some other countries, Australia has a group of Parliamentary Friends of Dementia (e.g., Parliamentary Friends of Alzheimer's Europe, and Parliamentary Friends of Dementia India). The group was launched in October 2003, providing another avenue for increasing awareness of dementia issues at the government level. There is also a New South Wales Parliamentary Friends of Dementia Group, established to support dementia as a national and state priority.

## **Lessons for future evaluation of dementia care in Australia**

Future evaluations should aspire to involve people with dementia and their carers at a number of levels:

1. Involvement of individuals directly in evaluation of services they are receiving.
2. Involvement at the level of advisory boards.
3. Involvement at a broader systemic level through judgements about whether services are matching priorities and meeting the needs of people with dementia as a whole.

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<sup>2</sup> Involving people in research; a national symposium on consumer and community participation in health and medical research. The University Club, Perth, March 5-6, 2008

The Consumers' Health Forum of Australia can facilitate such involvement. This is a national organisation funded by the Federal Government that provides a voice for consumers to participate in health decision-making at a number of levels, from the individual level to policy and planning levels. The HealthInsite Consultation topic page has links to information on consultation processes, including calls for submissions and requests for feedback. The site consists of 800 health topics with some 12,000 resource links, across 77 information partners. This may be a mechanism for carers of people with dementia to access evaluations of dementia care services. Evaluations in future may need to engage with the Consumers' Health Forum or the Health Issues Centre in Victoria (the Health Issues Centre took over some of the functions of the now defunct National Resource Centre for Consumer Participation).

At the policy level, Alzheimer's Australia has a National Consumer Committee (NCC) and State Advocacy Committees with a membership of both people with dementia and family carers. Individual members of the National Committee have had some involvement in advising on consumer involvement in research and in the more detailed policy work of Alzheimer's Australia. Most recently NCC members were involved in commenting on a survey for a project with Access Economics to determine preferences of consumers for different kinds of community support and preferences between community and residential care. Alzheimer's Australia Research provides an opportunity too for Alzheimer's Australia to test out consumer involvement in the activities of that organisation.

People with dementia are already being involved in the planning and development of services, in evaluation of services, in research, and in education and training, but these activities could be increased. Most of the current efforts at encouraging people with dementia to be involved in these different areas are being taken up by people with early dementia. The various advisory boards and other groups of people taking an active role in the development of services for people with dementia overseas were invariably populated by younger people in their 60s and 70s, a large number of them men with a professional background. A similar trend is noted here in Australia, where conference appearances are generally made by younger people with dementia and their families. Considerable resources would need to be expended to extend such participation to older groups if they were interested in being involved.

The model for participatory research used by Roulstone et al. (2007) in the UK would seem a good one to apply to dementia care evaluation in Australia. They used three groups to steer their research:

- (i) The research team: this consisted of three academic staff from the University of Sunderland and the co-ordinator of Sunderland Carers Centre.
- (ii) Carers' Participation Reference Group: Local carers were part of a carer participation reference group that also included academic researchers. This group managed the day-to-day operational aspects of the research.
- (iii) Research Review Group: This group involved carers and key carer stakeholders from England, Wales, and Northern Ireland. It met four times throughout the research and had a strategic overview of research progress.

It is immediately obvious that this amount of consumer input is expensive, and would add considerably to the total cost of research or evaluation. Efforts are now being made to evaluate whether the benefits would outweigh costs.

## Conclusion

The overseas initiatives summarised here are not intended to trivialise the substantial work being undertaken in Australia; rather this was an opportunity to reflect on further developing the work already being carried out on the role of people with dementia in the evaluation and planning of their services, research, and training.

The stand-out lessons learnt during this exploration were:

1. Some people with dementia who are young and diagnosed early are very keen to have a public role in the development of policy, services, and evaluation.
2. There are growing roles for such people, who can join groups to put their ideas forward, and there is both independent organisational support as well as government encouragement of such roles overseas.
3. People with dementia and their family carers find it satisfying to be involved in research and evaluation; it gives them confidence and makes them feel they are valued members of society.
4. Older people with dementia, and those with moderate to severe dementia, are mainly involved on a one-to-one basis in having a say about their own care rather than at a policy or service development level.
5. Advisory boards, working groups, and groups of people who have volunteered for policy development roles are not representative of the general population.
6. If such groups have priority setting roles, they should be supplemented with population surveys if the priorities assigned are to be truly indicative of what the community as a whole wants.
7. The UK health service has a strong consumer involvement ethos in all areas, not just in dementia care.



## Addendum: Alzheimer's Australia and consumer activities<sup>3</sup>

Alzheimer's Australia offers recognition and inclusion to people with dementia, and can serve as a model. In March 2008, two people with dementia were invited to give a plenary presentation at the Biennial National Conference. This presentation was enthusiastically received, and the speakers were treated with respect and honour.

The Australian Consumer Focus Group consists of people with early-stage dementia from around Australia, who provide input on policies and programs, drawing on their unique expertise from living with dementia. The Focus Group is also represented on the National Programs Steering Committee. Members of the Group share their perspective with professionals, care-partners, and the media (e.g., on national commercial and public broadcast television, and on radio networks).

There are early-stage support groups for people with dementia around Australia, as part of a developing nationally co-ordinated program. Australian people with dementia are included on the Board and on advocacy groups of state associations, and all state associations are developing approaches to policy and advocacy committees for people with dementia and their care-partners.

Alzheimer's Australia is currently planning a study of how to strengthen patient organisations around the world, addressing legal and medical issues in order to establish advocacy mechanisms for people with dementia and their care-partners, and the necessary structures and linkages.

Internet communication is often vitally important to people with dementia; their abilities to drive and to orally communicate may be limited, and yet they are geographically scattered. Alzheimer's Australia provides a welcoming, dementia-friendly website, offering clear information, ability to contact other people with dementia by email or in chat-rooms, and an invitation to contact the convenor of the focus group.

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<sup>3</sup> This Section was written by Alzheimer's Australia

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## Appendix 1

List of interviewees and contacts made during the study tour

Interviewee	Further contacts
Prof. Bob Knight, University of Southern California	Margaret Gatz  Kate Wilber
Prof. Margaret Gatz Professor of Psychology, USC	Debra Cherry, AA Los Angeles, interested in evaluation of dementia services.
Dr Debra Cherry, AA Los Angeles	
Prof. Andrew Scharlach, Professor of Aging UC Berkeley	<a href="http://www.link2care.net">www.link2care.net</a>
Prof Ann Mayo, Professor of Nursing, UCSF	
Dr Angela Kydd, School of Nursing, University of Paisley, Scotland	
Prof. Jill Manthorpe, King's College London	Steve Iliffe
Prof. Lou Burgio	
Dr Renee Beard	
Dr Liz Gould	Sam Fazio, Alzheimer's US, Chicago
Dr Peter Reed	
Dr Suzanne Sorenson	
Prof. Murna Downs	Caroline Cantley
Ms Andrea Capstick	Consensus conference, hosted by University of Central Lancashire, on user involvement in health and social care. Main organisers Paul Beresford and Penny Simmons
Ms Claire Surr	Commission for Social Care Inspection – over 100 care homes using a framework to ask people with dementia about their care
Mr Peter Woods	Carol Fusek, Singapore, international team identifying cost benefit analysis of dementia care mapping

Interviewee	Further contacts
Prof. Sube Banerjee	Jane Gilliard, seconded to Dept of Health
Dr Philip Bryers	
Scottish Dementia Working Group	
Dr Alan Chapman	Heather Wilkinson