

RESEARCH AND DEVELOPMENT NETWORK  
SCOPING STUDY REPORT  
FOR THE WELSH ASSEMBLY GOVERNMENT

April 2005

‘Alzheimer’s disease’

*Wales Dementias & Neurodegenerative Diseases Research  
Network*

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## **Executive Summary**

1. This scoping study report has been produced by an inclusive partnership of academic organisations, voluntary agencies, health and social care.
2. The proposed scope of a research network is ‘the dementias and neurodegenerative disorders (including Alzheimer’s)’, to remain consistent with the call for tenders for the UK Co-ordinating Centre. These conditions affect at least 47,000 people in Wales, a significant number of whom are of working age. Meeting their needs effectively continues to be one of the major challenges for health and social care services.
3. The study has indicated that there is a strong basis for research in this area to continue to develop in Wales. Currently funded projects bring in external funds of over five million pounds, and over 200 publications with input from researchers in Wales have appeared in the scientific literature over the last five years. Current research covers the whole range from basic biochemical and genetic research to research on service delivery and policy. There is a wide geographical spread of the current research.
4. Voluntary organisations in Wales in this field have strong grass-roots support, and have helped to foster partnership between professionals and patients and carers. They offer a tried and tested route for involvement of patients and carers in the research process.
5. There is strong interest from health and social care practitioners in developing services in an evidence-based fashion, in being involved in research activity and in implementing new findings and approaches.
6. Research in Wales could be strengthened by enhancing recruitment to studies, developing more collaborative approaches in Wales and building on existing

collaborations in the UK and internationally. Supporting research partnerships between practitioners and researchers is essential.

7. Although stakeholders could see the need for close partnership with other research networks, including mental health, primary care and older people, a need for sufficient support to enable a distinct network to operate for the dementias and degenerative disorders was emphasised. A distinct network is needed to allow a good match with the UK Clinical Research Collaboration priorities, and is consistent with the priorities of the Welsh Assembly Government, falling at the interface of the priorities of older people and mental health.

## **1. Introduction**

This report arises from a scoping study grant to the Dementia Services Development Centre, University of Wales Bangor, awarded by the Wales Office of Research & Development. However, responsibility for the proposal has been shared in a partnership including Universities active in this field, the Alzheimer's Society, the All-Wales Alliance for Research & Development (AWARD) and representatives from health and social care and primary care, from the Wales Collaboration for Mental Health and its associated All-Wales Improvement Network for Mental Health of Older People (see Appendix 3).

The aim has been to be as inclusive as possible. Two stakeholder meetings have been held (in Cardiff and Llandudno) attended by 60 people in total (see Appendix 1) and a number of people unable to attend responded to a widely-circulated postal questionnaire.

Discussions have been held with those responsible for scoping studies in related fields, including:

Mental health

Older People and ageing

Primary Care

Service quality (integrated care and programme development)

Risk assessment and risk management of harm to others

Discussions have also been held with Professor Sube Banerjee, from the Institute of Psychiatry, London, who has been commissioned by the UK Mental Health Research Network to carry out a scoping study on research in old age psychiatry (including dementia) in relation to the emerging themes of that work, and developments in relation to the UK Dementias network. Professor Banerjee gave a helpful presentation on this at the Cardiff stakeholder meeting.

## **2. The focus of the proposed network**

Following the lead of the conclusions of the MRC Workshop preparing for the UK Alzheimer's network (November 29<sup>th</sup>, 2004), the scope of an Alzheimer's disease research network was taken to include all the dementias, including vascular dementia, dementia with Lewy bodies, fronto-temporal dementia, Pick's disease, dementia related to Parkinson's disease etc.

The anticipated invitation to tender for the UK CRC Co-ordinating Centre for Alzheimer's disease was issued on 6<sup>th</sup> April 2005. This describes the scope as 'Dementias and neurodegenerative diseases (including Alzheimer's disease)'. As well as Alzheimer's, Parkinson's disease, Huntington's disease and Motor Neurone Disease are specifically cited.

Following discussion at the two stakeholder meetings held to inform this study, and consultation with members of the Wales Neurological Alliance (an umbrella body bringing together the patient and carer organisations in this field) there was clear consensus that the scope of the proposed network for Wales should be identical with that of the UK Research network, explicitly including other neurodegenerative

disorders, in order to ensure an effective partnership with the UK CRC Co-ordinating Centre.

The provisional working title of the network is accordingly:

## ***Wales Dementias & Neurodegenerative Diseases Research***

### ***Network***

#### **3. The scale and nature of the disorders**

The Alzheimer's Society estimate that there are over 41000 people with a dementia living in Wales. An equivalent, or greater, number of people will be involved in providing support and care to these individuals. Although the prevalence of dementia rises greatly with increasing age, a significant number of younger people also develop dementia (perhaps as many as 1000 in Wales). Population projections indicate a steady rise in numbers over the next 30 years, as the number of people surviving to age 80 and beyond grows, with corresponding increases in the costs of care services and in the costs to family and friends of providing support and care.

The difficulties associated with dementia are the most common reasons for people requiring care in the community or a place in a care home. Even in homes not specialising in the care of people with dementia, as many as three-quarters have significant cognitive impairment (Macdonald et al., 2002; Age & Ageing, 31, 58-64), but are seldom included in research studies. People with dementia are major users of mental health services and other forms of health and social care. Apart from the sheer scale of the condition and its effects, the unpredictable nature of dementia, its frequent co-morbidities and the natural history of increasing impairment in cognitive abilities,

make dementia a major challenge for all concerned in health and social care, including the research and practice communities.

Parkinson's disease is estimated to affect 6000 people in Wales. Most are over 50, with the prevalence increasing with age, but in about 5% of cases the onset is before the age of 40. The Parkinson's Disease Society has 20 groups meeting across Wales, providing a network of information and support for people with Parkinson's and their families. There are 9 Parkinson's Disease Nurse Specialists working across Wales. Parkinson's is a progressive neurological condition, leading to tremors, slowness of movement and rigidity. In a proportion of cases, cognitive changes may occur, perhaps leading to a dementia, and symptoms of depression are also common.

Huntington's Disease is an inherited condition, with onset usually between age 30 and 50. It is gradually progressive, with involuntary movements developing alongside emotional and cognitive changes.

Motor Neurone Disease is a group of related disorders which lead to progressive weakness and wasting of muscles. The highest incidence is between 50 and 70 years of age, and there are estimated to be between 200 and 300 people with the condition in Wales. Wasting of the muscles in the face and throat may lead to difficulties in speech and swallowing, but cognitive function is rarely affected.

These, along with a number of other rarer neurodegenerative conditions, form the focus for this proposed research network. They have in common the need for a multi-agency approach, involving health and social care and the independent sector

(including voluntary agencies). The relevant voluntary agencies, including those specific to each condition and the generic carers' support organisations, make a major contribution to the support needs of the people and families experiencing these disorders. The independent sector provides the bulk of the long-term residential and nursing home care which a significant proportion of people with these conditions require. These conditions require a multi-disciplinary response; neurologists, psychiatrists (for the dementias, including long-term care of people with Huntington's) and physicians in the medicine of old age are among the medical specialities with a major role to play. Nurses, including nurse specialists, occupational therapists, physiotherapists, speech and language therapists, social workers, genetic counsellors and clinical psychologists will also make significant contributions to the support, care and treatment needs during the course of these conditions. In each condition, degeneration can occur to the extent that palliative care may be required, with death often occurring from another cause, such as pneumonia.

#### **4. Existing research and development activity in the field**

In order to estimate the extent of research and development activity in the dementias and neurodegenerative diseases in Wales, two key indicators were selected. These were publications in peer-reviewed journals (published since 2000) and current funded research projects. These are shown in Appendices 3 and 4 respectively.

Publications were identified initially from literature searches of the major medical and healthcare databases (including Medline, Psycinfo and nursing databases). As active researchers in Wales were identified, further searches were carried out for other publications where they were an author, and they were also contacted directly and asked to supply a list of recent publications and current research grants, as well as being invited to stakeholder events. Institutional web-sites were also visited for publication lists.

Research grants were identified by accessing the lists of projects funded by the major funders (MRC, ESRC, Wellcome, WORD, Alzheimer's Society, Alzheimer's Research Trust, Parkinson's Disease Society etc.), the National Research Register, web-sites of academic institutions and contact with individual researchers.

In the time available, it has not been possible to check and cross-check each entry in Appendices 3 and 4, and there will certainly be omissions, changes of personnel etc. These lists must be taken as under-estimates of the actual research activity. What is evident is the extent of both peer-reviewed publications and funded projects. These demonstrate that Wales has a strong, broad research base in this field. It has been possible to identify current projects with a total funding in excess of five million

pounds, either led by research teams in Wales, or with a significant involvement from such teams. Funding is being attracted from the most prestigious and competitive sources, such as the Medical Research Council (MRC), Economic and Social Research Council (ESRC) and the major research charities. Over 200 peer-reviewed journal articles, published since 2000, have been identified, again involving researchers from Wales. This represents a strong and productive research community in this field in Wales.

The Alzheimer's Society clusters its research activity under the three broad headings 'Cause', 'Cure' and 'Care' and argues that research in each area is essential if progress is to be made. 'Cause' reflects basic, usually laboratory-based research, into underlying mechanisms of the dementias; 'Cure' refers to the development of new treatments and 'Care' to psychosocial aspects and clinical management. Our searches indicate that Wales has strengths in each of these three areas.

We have identified several major research groups who are involved in systematic programmes of work, with several current grants and a track record of publication over the last five years. These include:

Cardiff – Mike Owen & Julie Williams: genetic studies of Alzheimer's

Cardiff – Anne Rosser and colleagues: Huntington's Disease; part of European HD network; Brain Repair Group – Parkinson's disease

Cardiff – Huw Morris and colleagues: Parkinson's disease

Cardiff – Tony Bayer, John Gallacher and colleagues: therapeutic evaluations and cohort study

Wrexham – Andrew McCaddon and colleagues: basic biochemical studies

Glan Clwyd Hospital – Jolyon Meara and Peter Hobson: Parkinson's disease, including quality of life

Bangor – Bob Woods and Linda Clare: psychosocial interventions in dementia

Bangor and Swansea – Diane Seddon, Catherine Robinson, Judith Phillips and colleagues: evaluations of carer assessments and carer strategies (samples include high proportion with dementia or neurodegenerative disease)

Glamorgan – Morton Warner and Richard Williams: service and policy issues

Swansea – Johannes Thome and colleagues: genetic and psychopharmacology studies

Again this list is not comprehensive. However, it indicates clearly the range of research expertise, encompassing Cause, Cure and Care, and the geographical spread across Wales.

## **5. Strengths and weaknesses of research and development activity and structures covered by the review**

### *Strengths:*

- World-class research: Although judgements of research quality are notoriously complex and difficult, it is certainly justifiable to assert that world-class research is already happening in Wales in this field. This is demonstrated through the contribution of this research to academic departments having the highest ratings for research quality in the last Research Assessment Exercise, through funding support from highly competitive sources such as the MRC, ESRC etc., and through publication in internationally respected peer-reviewed journals.

- In Wales, there is already experience of large-scale patient recruitment and management of patient databases (such as in the MRC late-onset AD genetic resource led by Professors Williams and Owen)
- A range of disciplines is involved in this research, including psychiatrists, neurologists, physicians in geriatric medicine, nurses, laboratory scientists, brain imaging specialists, psychologists and social scientists
- Range of topics covering Cause, Cure and Care and projects directly relevant to policy and practice development
- Proven ability to attract external funding, from the pharmaceutical industry as well as from government and charitable sources
- An excellent range of collaborations with research groups elsewhere in UK and abroad, including the European Huntington's Disease Network (Rosser) and INTERDEM (European network for timely detection and psychosocial interventions in dementia care – Bayer, Clare, Woods)
- Proven ability to attract European funding for projects e.g. co-ordination of INFOPARK and Dignity in Care of Older Europeans projects
- Range of methodologies – e.g. laboratory based research, randomised controlled trials, qualitative research

*Weaknesses:*

- Recruitment – difficult across the board
- Disincentives from bureaucratic requirements for researchers starting out with small projects
- Alzheimer’s Society QRD membership in Wales relatively small – mainly carers
- Stakeholder meeting felt the Dementia Services Development Centre could fulfil a greater role in supporting research activity, but DSDC has never had core funding in Wales
- Many small studies (e.g. Masters’ projects etc.)
- Lack of WORD funding for projects in recent years (in the past, WORD grants were useful for career development for researchers)
- Difficulties in co-ordinating recruitment of large samples over several sites, and difficulties in maintaining follow-up (especially in samples of older people)
- Research expertise concentrated in a few centres and opportunity to undertake and take part in research not available to all across Wales

## **6. An outline of plans for developing a dementia and neurodegenerative diseases research network**

### *Strategy for developing user/carer involvement:*

At each of the stakeholder meetings, members of the Alzheimer's Society QRD network were present. They described the process whereby lay people, primarily carers and people with dementia, established the research priorities for the Alzheimer Society's research programme. Each proposal the Society receives is rated by a number of QRD members, and only those achieving a score above a threshold go onto further consideration. The 'lay-summaries' produced by researchers for the benefit of the QRD members often demonstrate the need for more contact between researchers and carers / people with dementia. Some QRD members then sit on grant panels, interviewing research teams alongside expert scientific members. Others are attached to a funded project, meeting the project team twice a year to seek feedback, monitor progress, suggest ways of increasing involvement etc. The Society organises training and support for QRD members in undertaking these roles. The Society's progress in achieving genuine involvement of carers and people with dementia in the research process has been recognised by several awards.

The Society also has a network of 22 Local Branches across Wales; most run Carers Support Groups and a number are also beginning to involve people with dementia in their activities. These local branches will also be able to assist in developing user/carer involvement in the work of the network.

In view of their well-developed expertise in this area, we would propose to commission the Alzheimer's Society to lead on this essential aspect of the network's function. The aim would be to build on the QRD approach, adding to the QRD network in Wales (to input to the Alzheimer's Society's research programme) and to develop additional capacity for input to the Wales network more generally; through the Wales Neurological Alliance, the Society would make links with other organisations such as the Parkinson's Disease Society, Huntington's Disease Association and Motor Neurone Disease Association to broaden the scope of the user / carer network to cover the range of disorders.

#### *Functions of the network*

Stakeholders identified the need in Wales for a network which would:

- Act as a source of information regarding research activity in Wales, to enhance collaborations and contacts
- Act as a resource for researchers, especially in relation to issues regarding ethics procedures and R&D governance in the NHS and Social Services, in the light of changes to legal frameworks
- Assist recruitment to research studies and clinical trials e.g. through an agreed protocol for 'consent to be contacted' to be used in Memory Clinics and other specialist centres where diagnoses are made
- Provide greater opportunities for patients / carers to be active participants in research
- Facilitate development of a Wales Brain Tissue Bank (in liaison with UK initiatives)

- Link with primary care (in collaboration with a generic primary care network)
- Link with the independent sector
- Be multi-agency, multi-professional and multi-disciplinary
- Have a regional structure
- Have efficient web-based information resources and databases
- Be responsive to research priorities of health and social care practitioners and managers
- Build on well-established links with the voluntary sector – at national and local branch level
- Be part of broader UK developments – being responsive to Welsh needs but keeping Wales alongside developments elsewhere and internationally

In order to fulfil these functions, the staffing profile required is likely to include the following:

- Academic lead (sessional) and associate leads
- Administrative support (sessional)
- ‘Research support officers’ – costed as G grade nurses – need 3 (perhaps sessional, seconded from services)
- Information / databases officer (web-site; maintaining data-bases etc.)

*Strategy for working closely with health and social care services*

The All Wales Improvement Network for Mental Health of Older People represents one forum where links with health and social care practitioners and managers could be developed and maintained; a need for promoting research in dementia –

particularly in service gaps relevant to social care was strongly made at the stakeholder meetings. Other networks would need to be accessed in relation to Parkinson's (perhaps through the specialist nurses) and other conditions.

#### *Link with UK CRC CC for the dementias*

The tender for the institution hosting the UK coordinating centre is due to be let in the summer of 2005. Depending on the time-frame of the Welsh Assembly making its decisions regarding networks in Wales, there is potentially the opportunity for being involved in the Board of the coordinating centre from the outset, with a reciprocal arrangement being made. The details of any working arrangement would need to be established, but it is envisaged that the network in Wales could take on, as far as resources allowed, some of the local network functions that will be the subject of later tendering in England, whilst retaining its distinct Welsh identity, focus and remit.

#### *Organisation of the network*

Three main options were considered. Firstly, that the network could form part of a joint network with a mental health network; secondly, it could be part of an older people's network; thirdly, it could stand alone. It was felt that the option of not pursuing a network to support research in this area would be completely out of keeping with the clear, stated priorities of both UK CRC and the Welsh Assembly Government, and so has not been considered further.

## OPTION APPRAISAL

### *A. Joint network with mental health*

#### **Costs:**

Would need to link to two UK CC's

Mental health would need more resources to operate a joint network – not much scope for savings based on economies of scale

Not good fit with neurodegenerative disorders – these are not seen as mental health conditions

Dementia would lack a distinct focus, and could be lost in a larger network

#### **Benefits:**

Would probably enable higher profile of other mental health problems in later life in mental health network also

Some cross-over of research

Many dementia services are part of a mental health section of an NHS Trust

### *B. Joint network with older people*

#### **Costs:**

Significant numbers of people with dementia and other neurodegenerative conditions are younger people

Not good fit with UK CRC

Most older people do not have dementia or a neurodegenerative disease

Risk of equating ageing and degeneration

#### **Benefits:**

Dementia services are often closer to older people's services (e.g. in social services)

Dementia a feature of large cohort longitudinal ageing studies

### *C. Stand-alone network*

#### **Costs:**

Need to avoid risk that Older People's mental health (other than dementia) will not be taken up by mental health research network

Need to ensure close linkage with other relevant networks

Need to explore where joint working can be productive (e.g. use of databases etc.)

#### **Benefits:**

Preferred option at stakeholder meetings

Manageable scope

Major issue in its own right

Extensive interface with social care and independent sector

Simple relationship to UKCRC

Could still benefit from close linkages with other networks

Distinctive needs of people with dementia and neurodegenerative conditions would be recognised

### *Appraisal*

Stakeholder opinion was divided as to whether, if a stand-alone dementia network were not to be supported, dementia research would be better served in a mental health network rather than on older people's network. Views were fairly strong in each direction, reflecting the position that dementia typically, and uncomfortably, holds at this interface. A stand alone dementia network would more effectively engage stakeholders, and through working closely with mental health and older people networks, duplication of effort can in any case be avoided.

A dementia network would also need to collaborate closely with other potential networks. In particular a strong primary care network is essential for the whole range of dementia studies to be undertaken. However, there would be no merit in a specific dementia primary care network (involving practices with an interest in dementia) as this would not be representative of primary care in general.

There would also need to be collaboration with a Learning Disability network, if funded, in view of the increasing recognition of the particular issues arising from the development of dementias in the context of Learning Disability.

Good links already exist with AWARD, and expertise in a range of approaches including Health Economics and Randomised Trial design.

The dementia network would wish to link with the network for Integrated Care and Programme Development (if funded), as it is recognised that the major investment that is envisaged in research networks will require careful attention to developing ways of using the resource effectively and productively, if the desired outcomes are to be achieved.

The network would also seek to work collaboratively with the Wales Industry Group, and other independent sector interests with a commitment to research.

*Priorities for first year of operation*

- Expand and develop QRD structure in Wales, led by the Alzheimer's Society in partnership with other voluntary agencies
- Develop working relationship with UK Coordinating Centre for the dementias and neurodegenerative disorders
- Establish regional presence, and develop protocol for patients to consider early in their patient journey whether they are happy to be contacted by research teams regarding participation in projects
- Establish web-site and virtual network of researchers, practitioners and patients / carers

**7. How would the network enhance research and development activity in this area?**

We envisage that the proposed network would:

- Increase recruitment in research studies and broaden opportunity for patients, carers and clinicians to be actively involved
- Remove obstacles, increase collaboration
- Facilitate involvement of people with dementia and carers – building upon existing examples of good practice in Wales
- Increase links with basic science research facilitating translational research
- Offer opportunities for Wales researchers to initiate large-scale projects through collaboration with other centres in UK dementia network
- Facilitate conduct of large, pragmatic trials of simple interventions across Wales
- Offer opportunities for people in Wales to participate in projects initiated by researchers elsewhere in UK through UK dementia network
- Bridge the gap between research and practice
- Act as a resource to assist people wishing to undertake research for the first time

## **8. Fit with Welsh Assembly Government priorities for health and social care**

A dementia network concerns itself directly with four of the Assembly's five stated priorities. It has been argued that dementia often falls between two stools – older people and mental health. Both are relevant. The majority of people with these conditions are older people; in the UK, care of people with dementia has often been undertaken by mental health services. Geriatric medicine has also been heavily involved in service provision for people with dementia. The decision to include dementia in the mental health chapter of the forthcoming National Service Framework for Older People attracted criticism from those who point out that dementia affects younger people also. This mirrors the controversy over whether dementia services should fall under the remit of older people's services or mental health services in NHS or social services, for operational or planning purposes. As part of our scoping study we have explored the pros and cons of including dementia in a larger thematic network (e.g. mental health or older people). As the option appraisal suggests, if the dementias have to be part of one or the other, then the fit will be far from perfect.

Involving people with dementia in influencing service development and research poses particular difficulties, in view of the effect of the condition on cognitive function. However, much good work has been done in this field, especially through the auspices of the Alzheimer's Society. People with dementia and their carers are now often participating and involved in planning of services and in Local Health Boards etc. The Alzheimer's Society QRD programme has a user/carers network, who have been supported in reviewing and commenting on research proposals, and form a key part of the Society's grant-awarding process. They also advise and assist in the monitoring of funded projects. The scoping exercise for this network has looked at the

lessons to be learned from this initiative, and it is proposed that a dementia network would work closely with the Alzheimer's Society to extend further its QRD network in Wales, with a view to ensuring that user/carer involvement is central to all dementia research activity in Wales. This approach would be consistent with the Involving Consumers in NHS Research initiatives.

Service quality is a major issue for services for people with dementia and their families. Reports (for example by CHI and the Alzheimer's Society) and research (e.g. Ballard et al., BMJ 2001, 323, 426-7) on quality of care regularly show difficulties in this area. These problems spill over into general hospital settings, which struggle to recognise and meet the special needs of people with dementia with physical health problems, resulting in unnecessary additional morbidity and avoidable delay in hospital discharge. Research on improving the quality of health and social care for people with dementia – in community and institutional contexts – and their families, needs to be developed further, paying attention to the implementation of the growing body of evidence-based practice. The Wanless Report emphasises the need for action based on evidence from research and the need for the redesign of secondary care to make better use of intermediate care and community facilities. Although not unique to dementia, if these issues can be tackled in the context of dementia, they have the potential to have a large effect on health and social care in Wales.

## **9. Fit with the work of the UKCRC**

A dementia thematic research network in Wales would, of course, relate directly to the planned UK Dementias network. The applicants are in touch with several of the major groups in England who are developing proposals to respond to the call for tenders for the Alzheimer's Coordinating Centre, and there is great interest in having a clear link with Wales. A Wales dementia network would enable research groups in Wales to participate fully in this initiative.

Just as importantly, having a dementia network in Wales would allow the development of an infrastructure whereby people with dementia and their carers could have more opportunities to participate in research studies, large enough to provide good quality evidence regarding new therapeutic approaches. Through networks of Memory Clinics and other specialist clinics and nurses, day hospitals, day centres and care homes, and establishing links with primary care networks, the perennial problems of inadequate sample sizes and shortage of suitable participants would be tackled systematically and research capacity would be built up. Research in Wales would benefit from participation in definitive multi-centre studies, across the UK, able to deliver research, quantitative and qualitative, of the highest quality. Enabling clinicians and practitioners in the NHS and social care in Wales to be more involved in research activity, through participation of more centres in multi-centre trials, has the potential to enhance the morale and professional development of dementia practitioners in Wales.

It is becoming increasingly clear that the consequences of not having an appropriate network in Wales would be that Welsh researchers would be at a major disadvantage

in accessing national research funds, people with dementia and carers in Wales would not have the opportunity to participate in major research initiatives and dementia would run the risk of being marginalized.

## **Appendix 1: Research priorities**

(themes emerging from stakeholder meetings and questionnaires returned)

### *Basic Research*

Working with basic research (more needs to be done before translational research)  
Studies to identify susceptibility genes and genes modifying course and outcome.  
Pharmacogenetic studies  
Identification of surrogate markers  
Welsh Brain Tissue Bank

### *Epidemiology*

Epidemiology e.g. Caerphilly project; as a basis for more refined services provision  
Prevalence – are there clusters of dementia or other disorders?

### *Particular populations*

Learning disability and dementia – accessing services, barriers  
Younger People with Dementia  
Alcohol related dementias - gaps in service provision  
Dementia related to Parkinson's, MND, Huntington's  
Vascular dementia

### *Therapies*

Pharmacological trials, effectiveness of drugs  
Platform for trials particularly psychological and social interventions  
Alternatives to drug therapies

### *Patient and carer perspectives*

Psychosocial aspects – the perspective of the person with dementia; what helps communication and interaction, quality of relationship between person with dementia and care-giver  
What to do individuals and their carers want?  
Person centred approaches

### *Service delivery*

What kind of care actually works?  
The effectiveness of statutory provision of support (Social Services /Health)  
Home care / day care; Domiciliary care in rural areas  
Use of technology

Memory Clinics – which ones work? Why?  
The influence of language on cognitive testing

Look at existing service models (in Wales and elsewhere)

Different kinds of residential care solutions for people with dementia  
Where will people with dementia live in the future? Models such as Shared Housing Schemes should be evaluated

Palliative care

Short-term interventions to prevent hospitalisation  
Going into care – what are the effects on the individual?  
What are the effects of the care pathway on well-being?

*Decision making*

Bournewood

Ethics

Capacity, consent and decision making

Going into care

Driving

Assessing capacity – who does it, how?

Human Rights implications

*Education and support*

What actually works?

For GPs? For Carers? For Home carers?

**Appendix 2: Stakeholder meeting participants:**

**Dementia Research Network for Wales  
7 & 14 April 2005**

<b>Name</b>	<b>Location</b>
Nick Andrews	Powys County Council
Sian Atkinson	Ysbyty Glan Clywd
Anthony Bayer	Cardiff University
Patricia Best	QRD, Alzheimer's Society
Barry Clarey	Pembrokeshire Mental Health Trust
Julie Davies	Gwent Health Care
Mike Davies	Mavalon Care LTU
Phil Davies	Alzheimer's' Society, Cardiff
Rhian Davies	Ysbyty Bronglais, Aberystwyth
Sue Davies	Sandy Lodge Nursing Home, Rhyl
Catherine Donnelly	Swansea NHS Trust
Pauline Edwards	Maelor Hospital, Wrexham
Paul Elson	Cardiff & Vale NHS Trust
Iona Evans	Royal Alexandra Hospital, Rhyl
Mark Fish	Cardiff University
Stephen Ford	Pembroke Nursing Home, Colwyn Bay
Valmai Hardie	QRD
Peter Hobson	Ysbyty Glan Clwyd
Rhian Hughes	Blaenau Gwent Council
Sanjay Ingley	Ysbyty Glan Clwyd
Ann Jones	Social Worker, Colwyn Bay
Helen Jones	Capricorn, Cardiff
Jane Jones	Sandy Lodge Nursing Home, Rhyl
Amanda King	Cardiff & Vale NHS Trust
Malcolm Liddell	North Glamorgan NHS Trust
David Linden	Univ of Wales, Bangor
Katrina McLaughlin	Bro Morgannwg NHS Trust
Rachael Litherland	Alzheimer's' Society
Christina Maciejewski	DSDC Wales
Sarah Morgan	Bro Morgannwg NHS Trust
Victoria Morgan	QRD Coordinator
Jane Mullins	Cardiff & Vale NHS Trust
Rob Nelson	Flintshire Adult Social Care Services
Anne Palmer	Memory Team
Catherine Poulter	Bridgend County Borough Council
Dianne Raphael	Craegmoor Health Care
Catriona Rainsford	Memory Team
Janice Rees	Gwent NHS Trust
Dave Roberts	Conwy Local Health Board

Hazel Roberts	Flintshire CBC
Julie Roberts	Maelor Hospital, Wrexham
Sally Roberts	Ysbyty Glan Clwyd
Alwyn Rowlands	Alzheimer's' Society, North Wales
Pauline Ruth	Gwent NHS Trust
Grace Sansom	Swansea NHS Trust
Diane Seddon	AWARD, UWB
E W Selly	Newtown Hospital, Newtown
Robert Sewell	Cardiff University
Alan Smith	Conwy County Borough Council
Nick Speller	Memory Team
Rowena Spencer	Conwy County Borough Council
Caroline Taylor	Ysbyty Glan Clwyd
Jo Waring	Memory Team, Cardiff
Diane Watkins	Monmouthshire LHB, Soc. Services
Julie Williams	Cardiff University
Karen Wood	North West Wales NHS Trust
Bob Woods	University of Wales, Bangor

## **Appendix 3: Scoping study steering group**

### *1. Name and institution of lead applicant*

Bob Woods, Professor of Clinical Psychology of Older People,  
Dementia Services Development Centre  
University of Wales Bangor

### *2. Names and institutions of co-applicants*

#### **Cardiff University**

Dr Tony Bayer  
Dept. of Geriatric Medicine

Professors Mike Owen & Julie Williams  
Dept. of Psychological Medicine

Professor Anne Rosser  
Brain Repair Group

#### **University of Wales Swansea**

Professor Johannes Thorne, Department of Psychiatry, Clinical School

#### **University of Glamorgan**

Professor Richard Williams, Professor of Mental Health Strategy,  
Professor Morton Warner, Professor of Health Strategy & Policy, Director,  
Welsh Institute for Health & Social Care

#### **University of Wales Bangor**

Dr Linda Clare, School of Psychology  
Dr David Linden, School of Psychology  
Dr Diane Seddon. Institute of Medical & Social Care Research, All Wales Alliance  
for Research & Development  
Dr Catherine Robinson, National Convenor and Director North Wales AWARD

#### **Voluntary sector**

Phil Davies, Manager for Wales, Alzheimer's Society

#### **Primary care**

Dr Huw Lloyd, Royal College of General Practitioners' Wales Mental Health in  
Primary care Network

#### **NHS**

Tom Woods, Corporate Support Manager, NHS Trusts Chief Executives Group

Dr Christina Maciejewski, Co-Director, DSDC Wales; Consultant Clinical  
Psychologist, Practice Development Unit, Whitchurch Hospital, Cardiff.

#### **Social Care**

Helena Thomas, Association of Directors of Social Services.

## Appendix 4: Publications since 2000

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### Appendix 5: Current funded research in Wales

Awarding body	Grant holder	Type of grant	Title	Amount (£s)	Time	Institute	Details
Alzheimer's Research Trust	Prof. John Harwood		Oily fish and Alzheimer's	300,000	2005-	Cardiff University	
Alzheimer's Society	Dr. Bastiaan Hoogendoorn	Fellowship grant	Comparative proteome analysis of the transgenic Alzheimer's disease mouse model	173,314	2002-2005	U Wales College of Medicine	Supervised by Dr. Lesley Jones
Alzheimer's Society	Dr. John Gallacher	Project grant	The pattern and causes of asymptomatic cognitive decline leading to dementia	154,065	2002-2005	U Wales College of Medicine	
Alzheimer's Society	Dr. Linda Clare		Functional and anatomical mechanisms underlying the effects of cognitive rehabilitation in early-stage Alzheimer's disease	140,000	2005-2008	University of Wales Bangor	With Bob Woods & David Linden
Department of Health	Dr Diane Seddon		The modernisation of social care services: a study of the effectiveness of the National Strategy for Carers	331,570	2003-2006	AWARD, University of Wales Bangor	With University of Wales Swansea

			in meeting carers' needs				
Eisai	Dr. A Bayer		Donepezil in vascular dementia (clinical trial)	40,000	2003-2006	U Wales College of Medicine	
Eisai	Dr. A Bayer		Donepezil in Parkinson's disease dementia	14,000	2002-2005	U Wales College of Medicine	
ESRC	Dr. Linda Clare		Awareness among people with moderate to severe dementia living in residential care	43,000	2005-2006	University of Wales Bangor	With University of Bradford
ESRC	Dr. Linda Clare	CASE PhD studentship	Motivations, meanings and relationships in family care-giving for people with dementia		2005-2009	University of Wales Bangor	With Bob Woods and 'for dementia'
European Commission	Dr. Linda Clare		Awareness in early-stage dementia: understanding, assessment and implications for early intervention		2003-2005	University of Wales Bangor	
European Commission	Dr. A Bayer		Informing the users	37,000	2003-2005	U Wales College of Medicine	
European	Dr. A Bayer		Dignity and older	655,000	2002-	U Wales	

Commission			Europeans		2005	College of Medicine	
Ipsen Fund	Dr. Huw Morris		Young onset Parkinson's disease	45,000		U Wales College of Medicine	
Lundbeck	Dr. A Bayer		Memantine in Alzheimer's disease (clinical trial)	100,000	2002-2007	U Wales College of Medicine	
Medical Research Council	Prof. M. Owen	Co-operative group grant	The genetic basis of neuropsychiatric and neurodegenerative disorders	577,738	2004-2009	U. Wales College of Medicine, Dept. Psychol. Medicine	
Medical Research Council	Prof. J. Williams	Programme grant	Detecting susceptibility genes for late-onset Alzheimer's disease	1,734,881	2004-2009	U. Wales College of Medicine, Dept. Psychol. Medicine	
Medical Research Council	Prof. R T Woods	Strategic grant	Reminiscence groups for people with dementia and their family caregivers: trial platform	227,049	2004-2006	University of Wales Bangor	With University of Bradford, University College London and Age Exchange
Medical Research Council	Dr. Manikkarasa Devakumar		MRC cognitive function and ageing study co-operative		2001-2006	North West Wales NHS Trust	

			group re-interview of survivors of original cohort				
NHS R&D Support funding	Dr. A Tales		Can tests of attention help to predict who with Mild Cognitive Impairment (MCI) will develop AD	7,200	2002-2006	Multi-centre, including Cardiff	
Parkinson's Disease Society	Dr. Anne Rosser		The capacity of human neural stem cells to differentiate into dopaminergic neurons	102,347	On-going	Cardiff University	
Parkinson's Disease Society	Prof. Stephen Dunnett		Choice reaction time in rats: effects of alternative cell repair therapies on deficits induced by dopamine cell loss		On-going	Cardiff University	
Parkinson's Disease Society	Dr. Huw Morris		A population based study of young-onset PD: clinical features, treatment response, quality of life and role of familial/genetic factors	210,000	On-going	U Wales College of Medicine	
Parkinson's	Dr. Monte		Identifying aberrant	87,431	Ended	Cardiff	

Disease Society	Alan Gates		gene expression by Glia from the substantia nigra in Parkinson's Disease		April 2005	University	
Parkinson's Disease Society	Dr. Rosemary Gates		Manipulation of precursor cells for the replacement of complex neuronal circuitry	50,000	Ended April 2005	Cardiff University	
Telethon	Dr. Anne Rosser		The development of strategies for the treatment of neurodegenerative disorders		2002-2007	Cardiff University	
University of Aberdeen.TauRx	Dr. A Bayer		TauRx in Alzheimer's disease (clinical trial)	20,000	2004-2006	U Wales College of Medicine	
Wellcome Trust	Dr. Linda Clare		Object and action naming and noun/verb comprehension in Alzheimer's disease	133,214	2004-2006	University of Wales Bangor	
Welsh Office of Research and Development	Dr. Diane Seddon		A study of the impact of the carers strategy in Wales on the needs of carers and the services they receive	189,941	2002-2006	AWARD, University of Wales Bangor	
Not recorded	Ms. Janice		Older adult		2003-	Gwent	

	Rees		normative data for the Rookwood driving assessment battery		2006	Healthcare Trust	
Not recorded	Dr. Huw Morris		A genetic investigation into the aetiology of parkinsonism and related conditions		2004-2009	U Wales College of Medicine	Multi-centre
Not recorded	Dr. Victor Aziz		Deficit in sensorimotor gating in Alzheimer's disease	42,662	2003-2005	U Wales College of Medicine	Multi-centre
Not recorded	Dr. Andrew McCaddon		Analysis of methylmalonic acid and holotranscobalamin in the Cognitive Function and Aging Study	24,000	2005-2007	U Wales College of Medicine, Division of General Practice, Wrexham	CFAS study (CFAS/COBALZ V)

