Delivering the National Dementia Declaration for England

Action plans
2010–2014

Dementia Action Alliance
www.dementiaaction.org.uk
Contents

Introduction to the National Dementia Declaration for England..........................................................5

Action plans

Age UK ...........................................................................................................................................6
All-Party Parliamentary Group on Dementia .................7
Alzheimer’s Society .................................................................8
Anchor..................................................................................................................................10
Association of Dementia Studies, University of Worcester ....................................................................12
Alzheimer’s Research Trust ..............................................................14
Association of Directors of Adult Social Services.................................................................15
Barchester Healthcare .......................................................................................16
Bradford Dementia Group, University of Bradford ........................................................................18
British Association for Counselling and Psychotherapy .......................................................................20
British Geriatrics Society .........................................................................21
British Association of Occupational Therapists and College of Occupational Therapists .............22
Bupa ......................................................................................................................................24
Care Quality Commission .......................................................................26
Care UK .......................................................................................................................................28
Chartered Society of Physiotherapy .................................................................30
Counsel and Care .......................................................................................................................32
Dementia Services Development Centre .................................................................33
Craegmoor ...............................................................................................................................34
Department of Health ..................................................................................................................36
English Community Care Association .................................................................38
Local Government Group .................................................................................................39
Four Seasons Health Care .........................................................................................40
Housing and Dementia Research Consortium .................................................................42
Jewish Care............................................................................................................................44
Mental Health Foundation .................................................................................................46
MHA ......................................................................................................................................48
National Council for Palliative Care .................................................................................50
NHS Alliance .........................................................................................................................52
NHS Confederation ...............................................................................................................53
National Institute for Health and Clinical Excellence ........................................................................54
Royal College of GPs ..............................................................................................................56
Royal College of Nursing ......................................................................................................58
Skills for Care ........................................................................................................................60
Royal College of Psychiatrists ..............................................................................................62
Parkinson’s UK .......................................................................................................................64
Skills for Health ........................................................................................................................65
Social Care Institute for Excellence .........................................................................................68
Southern Cross Healthcare .................................................................................................70
Thomas Pocklington Trust .......................................................................................................72
WRVS ......................................................................................................................................74
Stroke Association ...................................................................................................................76

Appendix

Template for action plans sent to organisations .............................................................79
Introduction to the National Dementia Declaration for England

Dementia is one of the greatest challenges facing our ageing society. There has been major progress in recent years in securing public and political commitment to responding more effectively to dementia. We now need to ensure that this commitment is turned into concerted action.

The National Dementia Declaration for England, published October 2010, declares a serious commitment to change the experience of living with dementia in England for good. It has been developed by people with dementia, carers of people with dementia and key national organisations who seek radical change in the way that our society responds to dementia.

The 43 organisations signed up to the Declaration have formed the Dementia Action Alliance. The Alliance calls on all families, communities and organisations to work with them to transform quality of life for the millions of people affected by dementia.

The scale of the challenge

There are 750,000 people living with dementia in the UK now and by 2025 there will be over one million. Dementia is an incurable condition caused by diseases of the brain which over time seriously impairs the ability of someone with dementia to live independently.

Families currently provide the majority of care and support for people with dementia and this can be both tiring and stressful – physically, emotionally and financially. A large number of people with dementia also live alone and can be at particular risk of isolation or abuse. However, if people with dementia are diagnosed early, and they and their families receive help, they can continue to live a good quality of life.

Action plans

All organisations invited to join the Dementia Action Alliance were asked to complete a template detailing their plans for delivering the outcomes from the National Dementia Declaration for England between 2010 and 2014. Everyone was asked the same three questions, and it is the responses to these questions that are documented in this publication.

There will be a quarterly report on the Declaration outcomes and an annual report on the progress of the action plans. All action plans and progress reports will be available on the Dementia Action Alliance website, www.dementiaaction.org.uk
Age UK

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

Age UK has a vision of a world in which older people flourish. We aim to improve later life for everyone through our information and advice, campaigns, products, training and research. We know that ageing is the main risk factor for developing dementia, but equally that dementia is neither an inevitable nor a normal consequence of ageing.

Age UK will work to influence the development of policy and services, nationally and locally, on how best to respond to the anticipated increase in the number of people living with dementia. We will support our partners in developing their services and sharing good practice, and will seek to find practical ways to make our own services more accessible to people with dementia and carers. We will offer training to those working in health and social care to improve their knowledge and skills in working with people with dementia, and we will continue to support high quality research into dementia and cognitive decline.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

Challenges for Age UK include:

- Supporting capacity development of local partners.
- Mainstreaming dementia into all our work – given the breadth of the work undertaken by Age UK.
- Routinely using our relationships/networks to influence others’ practice.

3. What are your plans as an organisation to respond to these challenges between now and 2014?

Age UK will:

- Support local Age UKs and Age Concerns to influence the development of local approaches to services for people with dementia and carers, and to share good practice.
- Publish examples of services offered by local Age UKs and Age Concerns which contribute to improving life for people living with dementia and carers.
- Continue to fund existing research projects into dementia and cognitive decline and consider proposals for new research.
- Work in partnership with a range of external organisations to influence public sector research priorities, with an aim of securing greater priority and funding for ageing-related research, including dementia.
- Offer training to people working in health and social care to improve their understanding of dementia and of effective ways of supporting people with dementia.
- In partnership with the My Home Life programme, produce a DVD for care homes on living with dementia, publish and disseminate information on best practice in dementia care for managers and staff working in care homes, and publish a special edition of the My Home Life bulletin on dementia for health and social care professionals and carers.
- Starting with information and advice, consider practical ways in which our services can be adapted to ensure that they meet the needs of people living with dementia and carers.
All-Party Parliamentary Group on Dementia

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

The All-Party Parliamentary Group (APPG) on Dementia is an informal cross-party parliamentary group made up of over 55 MPs and peers with an interest in dementia.

The APPG on Dementia works to raise awareness of dementia among parliamentarians, and influence legislation and government policy with the aim of improving the lives of people with dementia.

Chaired by Baroness Sally Greengross OBE, the Group meets several times a year and uses each meeting to focus on specific issues affecting people with dementia and their carers. It also undertakes other parliamentary activities such as producing briefings and holding inquiries, with the aim of making a positive difference in the lives of people with dementia.

At national level the APPG’s key role is to influence policy in a way that delivers improved quality of life for people with dementia. However, by engaging parliamentarians at this level it can also have a role in helping MPs foster local dementia supportive communities in their own constituencies.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

- The current and significant pressure on public resources is dominating the political agenda. The APPG must recognise this and ensure its work on dementia is relevant within this context.
- There are many time pressures on parliamentarians, and this means the capacity for members to meet as a group is limited. The APPG must then focus on a small number of big issues that affect the lives of people with dementia.
- There are many competing issues on the public and political agenda at this time. The APPG must ensure that dementia is prioritised among these issues.

3. What are your plans as an organisation to respond to these challenges between now and 2014?

- The APPG will work to ensure there is an effective voice for people with dementia in parliament by contributing to debates and questions in the house on issues affecting people with dementia and their carers.
- The next meeting of the APPG on Dementia in December 2010 will cover the National Dementia Declaration. Members will have opportunity to discuss the action plan of the Group and contribute new ideas to delivering outcomes.
- The APPG will conduct its next inquiry into the delivery of good quality and efficient dementia care services, reporting by summer 2011.
- The APPG will conduct an inquiry every year from now until 2014 that focuses on issues key to quality of life for people with dementia.
Alzheimer’s Society

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

Alzheimer’s Society is the UK’s leading support, care and research charity for people with dementia, their families and carers.

We provide information and support for those with any form of dementia and their carers. We advise and train professionals working in the field, fund research, run quality support and care services, and campaign for improved health and social care and greater public understanding of dementia.

We work in partnership with others to ensure that support is always there for people with dementia and that people receive a timely diagnosis, that the condition is understood and that people with dementia have the same rights as other members of society.

We will achieve this through funding scientific breakthroughs, strengthening communities by increasing understanding of the needs of people with dementia and the contribution of carers and striving to put an end to discrimination and stigma.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

Dementia is higher on the public and political agenda than it has ever been. We have seen action across England to begin implementing the National Dementia Strategy. The task at hand now is to use that strong position and build on the momentum achieved by creating a broad church of individuals and organisations committed to action.

Public awareness of dementia is rising but understanding about dementia is poor. There is limited public appreciation that it is possible to live well with dementia and to make big differences to quality of life for people with dementia and their carers. Poor understanding is something common among the general public as well as people working in health and social care services.

People with dementia are diagnosed too late and families often report not receiving the information and support they need to begin living well with dementia. People with dementia often face social isolation and poor outcomes.

There is a limited amount of funding going into dementia research compared to other major disease groups like cancer.

In a difficult economic climate we need to clearly make the case for action on dementia to achieve better outcomes in a cost effective way.

Most importantly we need to work with people with dementia, their carers and families to understand what matters most to them in order to transform quality of life for all people living with dementia.
3. What are your plans as an organisation to respond to these challenges between now and 2014?

• We will champion public understanding of dementia through national and local awareness campaigns, and by supporting people with dementia to speak out and tell their own stories.

• We will continue to develop quality information and support services for people with dementia, their carers and families through local information and support services, our website and helplines.

• We will use evidence from the demonstrator sites on dementia advisers and peer support networks to develop more and better services for people with dementia and their carers.

• We will improve the skills of the dementia care workforce by developing and delivering high quality education programmes to staff across a range of dementia care settings and through the use of our approved trainer scheme.

• We will work with people with dementia, their carers and families to campaign for a fairer deal on the issues that matter to them – early diagnosis, access to the right care and treatment, and investment in dementia research – and ensure their needs are recognised by decision makers at national and local level.

• We will fund a programme of research into prevention, cause, care and cure of dementia. We will increase the amount of money we spend on dementia research by 20 per cent per year.

• We will develop 150 local community dementia forums which will bring together people with dementia, carers, health and social care professionals and others to understand the local experience of people with dementia and work out solutions.

• We will work with a range of partners to develop evidence about cost effective interventions for people with dementia and their carers.

• We will work with partners to develop and publish evidence about dementia supportive communities.

• We will provide the secretariat for the Dementia Action Alliance and, working with the Alliance, publish an annual report on progress.
Anchor

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

We show absolute commitment to supporting and empowering all our customers living with a dementia by supporting all staff, not only direct care staff, with information and education.

We achieve this by:

• Structured training courses tailored to the needs of all staff and services; these courses range from awareness sessions to more advanced courses leading to dignity champion status. All cover an extensive variety of dementia related topics and we have a dementia knowledge development plan. We aim to empower people living with dementia by educating staff and effectively and enabling staff to signpost customers and family to community sources of additional support and information.

• We build on the training by providing a rolling programme and supporting and coaching staff and provide debriefing sessions to enable them to identify approaches and solutions to improve the lived experience of people with dementia wherever that person lives.

• We support current and future family and friends and with free education and information sessions and one to one support as needed.

• We are recruiting volunteers to meet individual needs to share and enhance life experience.

• We positively encourage people with dementia to influence the services we provide with residents forums across the different settings in which they live.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

• Meeting the need of all staff as staff leave and join the organisation, ie addressing turnover that can be high in some care settings.

• Ensuring solid effective management systems are in place to support staff, motivate, lead and inspire.

• Challenging values and attitudes amongst some staff and relatives that are misconceived about dementia or the person living with a dementia.

• Encouraging family and friends and staff to be active partners in care.

• Meeting the needs of people with dementia at different episodes along their journey, from diagnosis through to end of life.

• Ensuring people with dementia are continually empowered and central to all considerations about their life, care environment and support given.

• Ensuring people have access and choice to a diagnosis or the process of a diagnosis if they are exhibiting symptoms that suggest a possible dementia.

• Ensuring people with dementia are not prescribed drugs to ‘control behaviours’, ie antipsychotic drugs, unnecessarily.

• Reviewing the use of antipsychotic medication prescribed for people with dementia living in our care homes.

• That people living with dementia do not receive controlling or restrictive care that deprives them of their liberty, choice or personhood; the need to revisit and reinforce Anchor’s value base and approach to care and support with staff.

• Enabling people to have access to activities/hobbies/leisure pursuits they have always enjoyed relevant to their ability to engage.
3. What are your plans as an organisation to respond to these challenges between now and 2014?

- Continue to do what we do in question 1.
- We regularly reflect, review and amend as needed our services and systems of support for people with dementia and Anchor staff.
- Continue to build links with organisations in the local community and national networks to add value to our service and support for people with dementia and our staff.
- Employment of volunteer co-ordinator to support individuals’ interests.
- Supporting skills and knowledge of individual roles such as activity co-ordinators in our care homes.
- Review the use of antipsychotic medication in our care homes.
1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

The Association of Dementia Studies (ADS) at the University of Worcester comprises a multi-professional group of educationalists, researchers and practitioners who are expert in the field of person-centred dementia care and support. People with dementia, their families and their carers inform the work of ADS at all stages.

Our aim is to make a substantial contribution to building evidence-based practical ways of working with people living with dementia and their families that enables them to live well. We do this primarily through research, education and scholarship.

We are committed to a person-centred approach in all our work. This is our ethical code that values all people as unique individuals, is respectful of the perspective of different standpoints, and recognises the interdependence of all of us. We are committed to raising awareness, challenging stigma and improving quality of life and well-being.

We work from an international perspective, but with a central focus on improving the UK capacity for excellent dementia services. We work in partnership with health and social care providers, commissioners, charities, educational bodies and government agencies.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

The general public, commissioners, service providers, staff and professionals often feel ill equipped to know the best way to work with people with dementia and their families. Research and best practice evidence about dementia care and support is not readily accessible and understandable. Skills to support people with dementia have not been a priority within professional training and education. There is a need for multi-disciplinary and multi-agency support so that people with dementia can live well. There is also a need to listen to the opinions of people with dementia and carers who bring an expertise which no others can offer. They are experts in their own right and to ignore them defeats achieving a realistic and balanced judgement about the challenges. Theoretical perspectives, critical thinking, education and research evidence needs to develop across traditional academic and practice boundaries. ADS works across such boundaries to provide research and education that is accessible to all involved.
3. What are your plans as an organisation to respond to these challenges between now and 2014?

ADS was established in 2009 under the leadership of Professor Dawn Brooker. By 2014 we will contribute significantly to the knowledge and skills base in relation to people living with dementia and their families with regards to primary care, early diagnosis interventions, experiences of black and minority ethnic populations, personalisation, family care, intergenerational issues, eradicating abuse and neglect, ways of working with people with limited verbal communication, tele-care, creative activity interventions, life-story work, person-centred communication, commissioning and quality assurance, housing with care, care at home, acute hospitals, care homes, end of life care, advance directives and work-force competencies.

We are committed to the achieving the outcomes in the National Dementia Declaration through the following actions:

- Make a difference to the experience of people living with dementia by working proactively at the interface between the experience of those living with dementia, those developing care practice and those undertaking research to ensure real knowledge transfer and translation between these different world-views.

- Ensure that we work actively to include people living with dementia and their carers in all our endeavours.

- Identify centres of excellence in person-centred dementia care in primary care, early intervention, care at home, day services, intermediate care, personalisation, acute hospital care, housing with care, care homes and palliative care.

- Provision of research and development in the delivery of person-centered dementia care through funded research grants and PhD studentships.

- Provision of commissioned research and evaluation of new service models, innovative interventions and commissioning.

- Provide a range of specialist accredited dementia education and training opportunities for those involved in delivering care at all points along the pathway including early interventions, primary care, care at home, acute hospital care, intermediate care, care homes, specialist housing and end of life care.

- Deliver professional accredited leadership development programs for those directing, managing and commissioning dementia care services.

- Provide evidence-based consultancy to improve practice directly for providers of health, social care and housing.

- Contribute to the skills development of those working in training and education in dementia care.

- Contribute to the dissemination of the body of knowledge in person-centred dementia care through journal publications, books, media appearances and conference presentations.

- Provide multi-disciplinary seminars, conferences, workshops and networking events.

- Actively support the work of Dementia UK in the West Midlands.
Alzheimer’s Research Trust

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

The Alzheimer’s Research Trust’s (ART) ultimate aim is to fund scientific studies to find ways to treat, cure or prevent Alzheimer’s disease and other dementias.

We work in partnership with, and applaud the work of, other organisations focused on care and campaigning. ART focuses on research to offer hope for people with dementia and their carers. For example, a blood test to detect Alzheimer’s at the earliest possible stage is one area of research we are currently funding that could significantly improve the picture for people with dementia.

Furthermore, we are committed to raising awareness of dementia with the general public through better understanding of our research, scientific developments and real life stories to help people seek treatment and the best possible care as early as possible.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

The growing burden of dementia with an ageing population is not currently matched with a proportionate level of research funding from the UK government. ART was able to fund £4.3 million in 2010 for cutting edge research projects – the largest ever UK charity commitment to dementia research in a single year – but is calling on the government to increase this urgently to help find a cure and effective treatments as charities and industry alone cannot meet this challenge.

Research capacity in the dementia field is a challenge as it is significantly lower than in other disease areas. Attracting more scientists into the field could significantly improve the level of research and progress in the coming years.

Poor access to information regarding research and clinical trials is a barrier for people living with dementia and their carers who would be willing participants. Better dissemination of all UK trials and useful research information could lead to more people involved in research and ultimately better outcomes.

3. What are your plans as an organisation to respond to these challenges between now and 2014?

• Our record £4.3 million investment launches our new strategy to increase our research spending and supports 37 new projects including pioneering work on diagnosis using brain scans, further research on unraveling the genetics of the disease, and research into biomarkers which play a crucial role in diagnosis and understanding disease progression.

• We will continue to fund the best laboratory and clinical research put forward to us, with a marked increase in calls for grant applications and specific funding streams to boost capacity in important areas.

• We will continue to work with the government to stress the need for dementia research and to secure a more proportionate share of funding – for example through the Ministerial Advisory Group on Dementia Research.

• In 2011, we will be able to provide even more information on a new website for people with dementia and their carers to improve understanding and access to information.

• We will be undertaking a project working with scientists in our network to better understand research capacity in the field looking at encouraging more people into this area.
Association of Directors of Adult Social Services

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

The Association of Directors of Adult Social Services (ADASS) is an England-wide organisation for serving directors of adult social services. These directors work for local authorities, and are responsible for the commissioning and provision of social care for the authorities’ populations. They do this wherever possible in partnership with the local NHS, and in response to the needs and views of service users and carers.

ADASS is a leadership organisation, with the ability to influence, inform, support and encourage its members. It cannot bind any of its members to specific courses of action. However it can share good practice, and support and encourage individual councils to adopt it. It is a national voice for social care, and therefore influences the shaping and implementation of policy. It can promote partnership working through any discussions at a national level.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

Key challenges are:

- Assumptions, about what is possible and right for people with dementia, which may restrict choice and limit the scope for living as good a life as possible.
- The need to raise awareness and offer training to a workforce which operates across many and very different agencies in the statutory and independent sectors, and which is made up of a wide range of knowledge and skills.
- The state of the public sector finances and the impact on social care, which will need to play a full role in finding savings.
- The need to maintain and improve integrated arrangements with NHS partners for commissioning and delivery, at a time when these partners are undergoing significant structural change.

3. What are your plans as an organisation to respond to these challenges between now and 2014?

ADASS will help to meet these challenges by:

- Sharing good practice among its members, encouraging people to see what is possible for people with dementia to live full lives, and helping them to think through how to make this happen locally.
- Including dementia in its support to members about personalisation, so that people with dementia and carers benefit from this national policy.
- Supporting members to think through how to use existing investment to re-shape services in order to deliver better outcomes.
- Promoting the views of service users and carers.
- Offering information and advice to other organisations.
- Presenting to policy makers the views of service users, carers, and those who commission or provide services.
- Working with health partners at a local, regional and national level to promote integrated planning and delivery of health and social care.
I. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

Barchester Healthcare focuses on outcomes and improved quality of life for people living with dementia through its Memory Lane communities, assisted living and independent living options (helped through outreach). Important aspects of this approach include a commitment to person-centred care embodied in care plans developed with the individual. Person-centred care plans include cooking, gardening, music therapy and specialised activities based on reminiscence and life work. Predicated on the basis that dementia does not mean people cannot make a contribution to life, staff work to make the day meaningful, engaged and enjoyable. Care planning also involves relatives and a wide range of in-house nurses, therapists, hospitality specialists and professionally trained staff. Staff work with PCT staff on reduction of anti-psychotic drugs, rehabilitative work, the management of difficult behaviours and end of life care to prevent the need for disruptive and damaging hospital admissions.

Barchester Healthcare makes its presence felt nationally in the debate on dementia through engagement with national and local media, co-sponsoring the ‘Older People and the Media’ awards. Barchester works collaboratively with many reputable providers within the dementia field, sponsoring the UK Dementia Congress, Admiral Nurses and the ‘Music in the Air’ challenge with the National Association for Providers of Activities for Older People. Barchester also develops dementia cafes with Dementia UK and Alzheimer’s Society. Barchester supports innovation for people with dementia and attracted much national publicity and public support for its booklets for children of grandparents with dementia and its work on pilot Quality Accounts.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

The National Dementia Strategy is right to emphasise the importance of early diagnosis of dementia: diagnosis in residential homes (and discussion of diagnosis with relatives) is also vitally important. Dementia care pathways need to be better mapped out and to include collaborative work with health commissioners on avoiding unnecessary hospital admissions; recognising that good residential care is a better and less expensive option for people with dementia and/or continuing care needs. This must involve clear agreements on funding, greater attention to transfer of important information and a willingness to define required goals and outcomes.

There is a clear and urgent need for a government sponsored, sustainable and fair framework for the funding of long term care generally.

There is an equal need for the sector concerned with dementia as a whole to gather together to build on its lobbying strengths and to work on positive publicity for its achievements.
3. What are your plans as an organisation to respond to these challenges between now and 2014?

- To continue to work collaboratively with health commissioners and providers on establishing better dementia care pathways, refining Quality Accounts to produce information on outcomes, quality of life issues and costs.

- To build on our training frameworks, incorporating Qualifications and Credit Framework and new guidelines and offering staff training focused on the importance of choice, care planning, activities, collaborative work with therapists and work with relatives.

- To continue to work collaboratively with local GPs and other health team members on early diagnosis, the reduction in use of anti-psychotic drugs and the avoidance of unnecessary hospital admissions.

- To continue to develop approaches for improving the quality of life of all residents (including those living with later stage dementias) through dementia mapping and matching to appropriate environments, communication activities and techniques.

- To work on the development of audit tools that ensure we facilitate the highest quality of life, can demonstrate delivery of clearly defined outcomes for our residents and that we involve residents and relatives in planning and managing change.

- To support individuals and family members through our charitable organisation The Barchester Foundation and to continue to work collaboratively with carers and local organisations representing people with dementia in order to develop community links and offer support and advice through dementia cafes, in-reach and out-reach work.

- To develop a capacity to help people living with dementia and their relatives manage personal budgets, maximise their effectiveness and report back on outcomes to health commissioners.

- To work collaboratively with health sector employees to improve communications around outcomes and quality reporting for people living with dementia and to offer training and work experience to health personnel where appropriate.

- To continue our joint work with groups representing people living with dementia, their relatives and professional development within the sector, expanding collaborative projects and developing our joint lobbying capacity.

- To continue to join in the public debate about dementia, to vigorously demonstrate that a high quality of life is possible for everyone living with dementia and to stand against the stigmatisation of the illness at a local and national level.
Bradford Dementia Group, University of Bradford

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

This document provides an overview of the University of Bradford’s Dementia Group action plan that has been designed to support the delivery of the National Dementia Declaration.

The University of Bradford is pleased to endorse the key principles detailed in the National Dementia Declaration and fully supports the participation of its internationally renowned Bradford Dementia Group in this national campaign to enhance the experience of living with dementia. As a leading academic unit, the Bradford Dementia Group contributes both to the development and application of evidence-based dementia care, in partnership with people with dementia, carers, service providers and organisations involved in dementia care.

The role of the Bradford Dementia Group in delivering better outcomes for people with dementia and their carers centres upon the successful delivery of our three core areas of business: education and training, research and consultancy. Bradford Dementia Group has already impacted positively on the outcomes for people with dementia and their families as evidenced by its effective education and training programmes, its research and its academics who lead the field in influencing practice and challenging and shaping policy.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

The challenges we face in delivering for people with dementia and their family carers include:

Education and training
• Lack of a mandate for practitioners and professionals to have dementia-specific knowledge and skills.
• Lack of career structure for dementia professionals and practitioners.
• Lack of employer engagement in selecting and supporting students for professional development. One consequence of this is the lack of mechanisms for students to cascade and disseminate this information on return to their workplace.
• Belief that training alone changes practice when, while it is a necessary ingredient, it is insufficient on its own to effect practice change.
• Reduction of funding to support students in seeking dementia specialist knowledge and skills. For example reduction of NHS multi professional education and training budget. Reduced budgets in local authorities.
• Lack of leadership in dementia care settings to which students return.
• Lack of public and professional understanding that there is anything to be learned about dementia care.
• Lack of real world examples of excellence in dementia care practice and services to which students can be exposed.
• Staff undertaking education and training are not provided with adequate support to study, eg sent straight from night duty to training session, not provided with study time and are expected to do it all in their own time, funding withdrawn part way through a course.

Research
• Relatively recent interest in health and social services (care) research into dementia (somewhat overshadowed by, itself poorly funded, research for cause and cure).
• Difficulties in embedding cutting edge research findings into dementia practice.
• Difficulty in researching effective programmes for sustainable change as time period is outside most funding periods.
3. What are your plans as an organisation to respond to these challenges between now and 2014?

Our 10 priority areas from now until 2014 are:

<table>
<thead>
<tr>
<th>No.</th>
<th>Action</th>
<th>By when</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>We are committed to further developing the engagement of people with dementia and family carers in the design, delivery and evaluation of our education and training, research and consultancy projects.</td>
<td>Ongoing until end 2014</td>
</tr>
<tr>
<td>2</td>
<td>We will actively engage with our key health and social care partners to ensure our strategies related to dementia care are aligned and will seek to establish shared projects that will impact on the self worth and sense of control of people with dementia and carers.</td>
<td>Ongoing until end 2014</td>
</tr>
<tr>
<td>3</td>
<td>We will actively engage in positive action with our students, people with dementia and carers, community groups and staff to reduce the stigma that can be associated with dementia.</td>
<td>Ongoing until end 2014</td>
</tr>
<tr>
<td>4</td>
<td>Dementia care will remain a key research focus for the University and we will invest in staff time to allow our researchers to create new knowledge that will translate into improved outcomes for users and carers.</td>
<td>Ongoing</td>
</tr>
<tr>
<td>5</td>
<td>We will further develop our education and training in order to widen access to all strata of the health and social care workforce, working in partnership with people with dementia and their families.</td>
<td>2011–2014</td>
</tr>
<tr>
<td>6</td>
<td>Bespoke consultancy service will be further developed to assist organisations and individuals to transfer research into practice in a timely and appropriate manner.</td>
<td>From early 2011</td>
</tr>
<tr>
<td>7</td>
<td>We will seek out opportunities for our key academics and researchers to collaborate on research bids and ensure we disseminate research in a timely and effective manner.</td>
<td>Ongoing until 2014</td>
</tr>
<tr>
<td>8</td>
<td>To maximise the accessibility of education and training programmes we will ensure our pricing and costing methodology means we can offer affordable education and training to the full range of employers and individuals.</td>
<td>Ongoing until 2014</td>
</tr>
<tr>
<td>9</td>
<td>We will continue to provide a forum for public and professional engagement and debate regarding the best approaches to meeting outcomes of direct relevance to people with dementia and their families.</td>
<td>Ongoing until 2014</td>
</tr>
<tr>
<td>10</td>
<td>We will support our key academics to work alongside people with dementia and their families to influence national and international policy in dementia care.</td>
<td>Ongoing until 2014</td>
</tr>
</tbody>
</table>
The British Association for Counselling and Psychotherapy (BACP):
• Values integrity, impartiality and respect.
• Embraces a diverse range of counselling and psychotherapy approaches.
• Promotes equality of opportunity.
• Consults widely.
• Advocates accessibility for clients to counsellors.
• Undertakes research.
• Responds to emerging issues and trend.
• Is enterprising.

3. What are your plans as an organisation to respond to these challenges between now and 2014?
• BACP will commission research into the effectiveness of counselling for carers of people with dementia and the qualitative experiences of those carers.
  – BACP has commissioned the University of Manchester to conduct a systematic review entitled, *Counselling and psychotherapy for the carers of those with dementia: a systematic review of the research literature*. The team comprises Dr Ruth Elvish and Dr John Keady who will begin the project in early January 2011. The review aims to systematically review existing research and identify the effects of interventions and implications for policy and practice.
  – The University of Manchester has also been commissioned to conduct a qualitative project entitled, *Investigating dementia carers’ experiences*. This project will investigate the experiences of those caring for a person with dementia, exploring their emotional and psychological needs. The focus of the study will be on the potential role counselling and psychotherapy can play in providing support for carers of those with dementia.
1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

British Geriatrics Society (BGS) members are involved in a number of aspects of care delivery for older people: acute sector, liaison services, day hospital, intermediate and community care and palliative care. Therefore early detection and institution of management processes for those with memory problems can be facilitated. Some members are the main providers of memory clinics in their area and can take local and national lead roles. BGS can influence the trajectory of acute admission through recognition of dementia and ensuring patients with dementia receive the priority they deserve. As a part of each component of service delivery BGS members can ensure patients with dementia are recognised and appropriately managed. BGS has a Cerebral Ageing and Mental Health Special Interest Group (SIG) which has already produced an educational document Delirious about Dementia, designed to facilitate early diagnosis and management. This SIG has an executive committee representing all regions in England as well as each of the devolved nations. BGS would endorse a local champion for dementia in geriatric medicine for each acute hospital. The training programme for this initiative would be delivered by SIG members regionally with assistance where needed from Royal College of Psychiatry, Old Age Section. BGS SIG can also provide education and training for primary care physicians in conjunction with Royal College of General Practitioners. BGS should also recognise the importance of supporting research into all aspects of dementia.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

Key challenges include an understanding for geriatricians about many aspects of dementia. This ranges from early detection and differential diagnosis through management with drugs for dementia to management of neuropsychiatric symptoms and indeed recognition of when to implement a purely palliative approach. The core curriculum for trainees in geriatric medicine should be examined to ensure that all these issues are addressed during specialty training. In a similar vein the challenge is to ensure that all postgraduate training programmes, not just those for geriatricians, contain sufficient information on dementia. Thus provision of education and training are the main challenges. These can be delivered in conjunction with Royal College Physicians. The ability of members to deliver such education is a major consideration.

3. What are your plans as an organisation to respond to these challenges between now and 2014?

• Delirious about Dementia document relaunch.
• Regional and devolved nation representation on SIG committee.
• Consultee to NICE on the Drugs for Dementia Guideline 2010.
• Document on pain assessment in the older patient (British Geriatrics Society, British Psychological Society, Royal College of Physicians).
• Document on Pain management in older people should include dementia.
• BGS statement on mental capacity 2010.
• Regional study days to facilitate local hospital leads for dementia.
British Association of Occupational Therapists and College of Occupational Therapists

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

The British Association of Occupational Therapists (BAOT) and College of Occupational Therapists (COT) are the professional body and trade union for occupational therapy staff, researchers, educators and students in the United Kingdom. COT supports members:

• In knowledge management, particularly in the areas of research and development, research governance and information management.
• In practice with expert resources and guidance and by defining standards for the profession.
• By producing COT-driven strategies to promote excellence in practice and client-centred care.
• Through involving them in developing and promoting the profession.

COT plays an active and visible role in the development of improving services for people living with dementia. Current actions to support this include: attendance at relevant conferences; promotion of materials to educate and promote best practice for people living with dementia; provision of web based materials to support NICE guidance; response to consultations and briefings on the dementia strategy; involvement in the Memory Services National Accreditation Programme and working with other organisations and professional bodies- for example reviewing and updating a number of Alzheimer’s Society factsheets. COT works alongside and supports the Specialist Section for Older People that hosts a clinical forum for dementia.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

The two main challenges for COT will involve:
• Empowering members, regardless of clinical setting or specialty, to feel confident to work effectively and safely with people living with dementia, their families and carers.
• Challenging society’s acceptance that people living with dementia cannot be supported to lead meaningful and active lives.
3. What are your plans as an organisation to respond to these challenges between now and 2014?

COT will be supporting the Dementia Declaration through six key actions.

1. Promoting awareness and understanding of dementia to occupational therapy staff working within acute, medical and community services.
   - Action: A resource consisting of a series of documents that will cover areas of care ranging from assessments, delirium, feeding, homes visits and discharge planning. Each document will contain a summary of evidence and standards and signpost further reading and resources. To be completed by December 2011.

2. Promoting the National Institute for Health and Clinical Excellence (NICE) Public Health Guidance 16, occupational therapy interventions and physical activity interventions to promote the mental wellbeing of older people in primary care and residential care (2008), through the Activity Matters Toolkit. The toolkit will be available electronically on COT’s website with resources and ideas for implementing the guidance for older people, including people with dementia.

3. Review existing or produce new resources to advise carers on different aspects of daily care with partners from other organisations. For example, in collaboration with the Chartered Society of Physiotherapy, COT intends to produce a resource for carers of people with dementia, to support them to identify strategies to manage seating, postural support and the physical management of their family member or client safely and effectively.

4. Promote an understanding of the nature of occupation and its importance to health and well-being and the contribution that occupational therapists make to services for people living with dementia.
   - Actions:
     - Designing and publishing leaflets for the public outlining the role of occupational therapy working with people living with dementia – December 2010.
     - Involvement in the Memory Services National Accreditation Programme through membership of the Standards Development Group and Accreditation Committee.
     - Producing a resource document on commissioning and planning occupational therapy services for people with dementia.

5. Develop resources for occupational therapy staff to implement recommendations within the End of Life Care Strategy for people with dementia.

6. Support occupational therapy practitioners to extend the scope of their practice beyond the boundaries of statutory health and social care services to meet the wider occupational needs of individuals living with dementia. For example, within care homes. Actions to be developed and completed by 2014:
   - Explore joint working with National Association for Providers of Activity (NAPA).
   - Exhibit at conferences (for example, the DSDC Coming of Age: Dementia in the 21st Century conference) and facilitate seminars.
Bupa

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

The main roles of Bupa Care Homes relate to the delivery of continuing quality of life to people in the later stages of dementia when their needs are complex and potentially challenging to carers and the continued involvement of their families and local communities in their lives. This is a time when many, often including the families themselves, fail to recognise the continuing personality and rights of our residents. Over-prescribing of anti-psychotic drugs, to deal with behaviours that challenge, can also significantly compromise life quality.

Our Person First approach to care is built around a deep understanding of and respect for the continuing personality of every resident, as a means to delivering positive, personalised engagement and an environment and spirit of community which enable that. This commitment to personalised care is reliant for its success on partnerships with a number of other stakeholders prior to care home admission.

Bupa will work to support earlier diagnosis and information provision which enable people to plan appropriately, particularly through life-story work and advance directives. We will continue to encourage more and better training of NHS staff and reduced prescribing of anti-psychotics by them, particularly recommending that our Dementia Champions initiative is taken up by hospitals. We will work with others to provide a much more supportive and integrated pathway of care.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

The key challenges to our ability to deliver Person First care are:

• Failure to diagnose early.
• Poor information and minimal support to people post-diagnosis resulting in isolation, medical emergencies and crisis admissions to care homes and hospitals.
• Insensitive treatment of people with dementia in general hospitals due to poor knowledge and leadership.
• Insufficient personal information about new residents due to lack of continuing relative involvement and/or of life-story work well before admission.
• Inappropriate prescribing of anti-psychotics and insufficient review of their continued use.
• Insufficient community involvement in our homes because of fear and taboos arising from poor public understanding.
• Inadequate public funding of dementia care in care homes which compromises staff quality and numbers and, as a consequence, the lifestyles we can provide for residents.
3. What are your plans as an organisation to respond to these challenges between now and 2014?

- Continue to improve public understanding through press, TV and web advertising, information on our website and the distribution of our booklet *Caring for someone with dementia*.

- Encourage people to plan for their future by providing printed and on-line materials to enable life-story work and advance directives.

- Continue to work with Alzheimer’s Society to train a Dementia Champion for every dementia specialist community (currently 192 trained) and encourage the NHS and other care providers to follow this example.

- Use our newly launched suite of dementia training modules (developed with the University of Bradford and others) to train every staff member in our dementia specialist communities in the basics of Person First care; senior members of staff in more advanced care; and specialist staff in appropriate skill areas eg nutrition, activity provision, palliative care etc. Complete this in 2011, maintain and develop it thereafter and extend training to non-specialist units by 2014.

- Establish the concept of Meaningful Moments to encourage brief but positive engagement with residents by all staff at every opportunity.

- Create internal and external environments that preserve privacy, enable quality of life and support activities of daily living.

- Ask the prescriber to review the use of anti-psychotics soon after admission and regularly thereafter, if continued.

- Ensure that each resident has a respectful and dignified death in line with the principles of Person First and that families are reassured by this.

- Engage with policy-makers at national level to support the implementation of the National Dementia Strategy.

- Continue to lead practice in care homes and be evangelists for best practice in person-centred care.

- Ensure continuity of care by involving the family, local community and primary care and by maintaining the same care setting until the end of life.
1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

The Care Quality Commission (CQC) is the independent regulator of all health and adult social care in England. Our core statutory functions include:

- The registration of health and social care providers to a common set of quality and safety standards, and monitoring their ongoing compliance with these registration requirements.
- Powers of escalation and enforcement where services fall below the essential quality and safety standards.
- Visiting patients whose rights are restricted under mental health legislation to ensure their rights are protected.
- Carrying out periodic reviews of the performance of providers and commissioners (quality assessments) in adult social care.
- Undertaking special reviews and studies of particular aspects of care.
- Publishing information to drive choice, change and improvement.

CQC has an essential part to play in relation to improving the quality of care and support provided to people with dementia. Our core functions and vision as described above enable us to make a significant impact on the successful implementation of the National Dementia Strategy in all care settings.

Our position statement and action plan in relation to care of older people and people living with dementia (published on our website) is directly informed by the views of people with dementia, their carers and the key stakeholders with an interest in this area.

We have identified three key areas for improvement where CQC would like to make a difference over the next five years:

- Ensuring that the care of people with dementia becomes more people-centred, including a greater focus on person centred care plans.
- Ensuring that people with dementia receive care that meets essential standards of safety and quality.
- Improving the commissioning of services for people with dementia.

In addition to ensuring that service providers meet the essential standards of quality and safety we also need to:

- Improve and share widely our information/intelligence on dementia care.
- Improve upon our methods of engagement with people with dementia who use services and their carers with a view to understand the relevant issues.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

Although there are challenges, we have drafted our position statement and action plan so as to ensure that our plans are relevant, achievable and compatible with our strategic priorities.

There will inevitably be challenges to providers in relation to meeting outcomes during a period of financial constraints and organisational restructuring. The external regulatory scrutiny on essential safety and quality will help ensure that people can nevertheless expect certain essential outcomes.

The sharing of good practice and innovative local solutions becomes particularly important within this context – making these available and transferable to both health and social care remains a key challenge – other organisations signing up to the declaration will play an important role in meeting this challenge.
3. What are your plans as an organisation to respond to these challenges between now and 2014?

Whilst the position statement and action plan covers what CQC will do over five years, in the first year following publication of the plan we will focus on the following as priorities:

- **Getting the basics right through registration**
  - ensuring that regulated services for older people and people living with dementia meet essential standards of safety and quality. There are specific regulations and standards which cover a number of areas and are of particular importance in defining what good quality care for people with dementia will look like such as:
    - Care and welfare of people who use services (Regulation 9) – in our standards document we promote a person-centered approach to the care and treatment received.
    - Respecting and involving people who use services (Regulation 17) – we describe expectations about how people will be involved in decisions about their care and treatment and how privacy and dignity will be respected.
    - Safeguarding vulnerable people who use services (Regulation 11) – we describe what services must do to respond to and prevent abuse and ensure that restraint is only used in appropriate circumstances.
    - Meeting nutritional needs (Regulation 14) – including encouraging and supporting people to receive adequate nutrition and hydration.
    - Management of medicines (Regulation 13) – including the requirement for complex drug regimes to be reviewed and to monitor the effect of medicines and take action in relation to adverse effects.
  - Requirement relating to workers (regulation 21) – we have made specific reference to staff in social care services that support people with dementia receiving training that satisfies the learning outcomes in the Skills for Care knowledge and skills set on dementia.
  - Co-operating with other providers (regulation 24) including sharing information in relation to the admission, discharge and transfer of people who use services.
- **Developing and implementing observational methodologies including SOFI 2 (Short Observational Framework for Inspection) to ensure that we capture the experiences of people who have cognitive or communication difficulties which affect their capacity to voice their opinions.**
- **Completion of our special review of healthcare in care homes which we anticipate will highlight issues in relation to older people and people living with dementia and follow up on the findings.**
- **Developing policy briefings and focused additional guidance for operational staff to ensure awareness of relevant issues for older people and people living with dementia.**
- **Establishing a new older people’s advisory board and smaller dementia reference group to actively engage with stakeholders and people who use services so that they can inform and influence our work.**

We would encourage people to access the full text of our position statement and action plan at www.cqc.org.uk for further details of these and our other proposals.
Care UK

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

As a major service provider, we play a key role in delivery of the outcomes contained within the declaration. We are also in the unusual position of having the ability to provide care across the spectrum of health and social care services through our broad range of service types.

We are committed to improving the quality of partnership working at both a local and a national level (internal and external) and will seek to achieve this by developing a more joined-up approach between our services internally and by influencing those external agencies with whom we work to deliver better services. This approach will shape the nature of care by improving services, improving efficiency, improving care pathways and delivering care that is outcome focused.

We seek to achieve these improvements by:

• Having a clear and unambiguous commitment to putting our service users first.
• Improving service user involvement and engagement.
• Improving partnership working between agencies.
• Continuing to develop a skilled and motivated workforce.
• Investing in the built environment.
• Improving health and social care outcomes from diagnosis to the end of life, in the community, in our hospitals and in our care homes.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

Within the two key areas stated above there are a number of challenges.

Whilst training has been recognised nationally as a key driver in achieving improved standards of care and delivery of care that is outcome focused, there is limited funding available to deliver this training. There are also huge differences in availability of training courses that can be accessed by the independent sector and these differences are dependent upon their location.

Whilst in-house training is more deliverable it is not without challenges, where there is high staff turnover, difficulty in ensuring that time is made available for staff to attend training courses and a lack of any agreed core curriculum.

Engagement of service users is integral to understanding their needs, wishes and expectations. Challenges arise when caring for those who are in the advanced stages of dementia, when communication may be severely impaired or non-existent and identifying what is wanted even on a basic level becomes very difficult.
3. What are your plans as an organisation to respond to these challenges between now and 2014?

To provide solutions to some of these challenges we are steadily moving away from sending staff on training courses outside of their home services. Within our Residential and Community Care services we are already utilising the provision of e-learning for dementia training with this being supplemented by more traditional training sessions held within the individual services.

Within our Residential Care Services we are also delivering experiential training to capture not only the ‘what is dementia’ but also ‘what it may feel like to have dementia’ as well as strategies that focus on non-medical approaches and the impact of the environment on the resident.

Our service development teams work with members of the operational teams and outside experts to ensure that the designs of all new builds take into account the needs of residents with a dementia when designing internal and external environments as well as ensuring that the internal designs (colour, signposting, size of units, lighting etc) are providing a positive impact and are fit for purpose.

Our proposed approach to the development and operation of dementia care services within our residential care sector can be categorised as coming within four key themes:

- Leadership
- Expertise
- Training
- Philosophy

The key elements of the themes can be summarised as follows:

- Dementia Leads to be in each care service to promote best practice and continuous improvement. The Dementia Leads within the services will receive training to ensure that they can act as mentors and coaching within their individual services.
- Dementia trainers to deliver experiential training.
- Further focus, training and development of activities (including Activity Based Care) in our operations to promote physical, social, spiritual, psychological well-being.
- Environmental improvements to our existing facilities where these would lead to quality of life benefits for customers.
- New builds to be fit for purpose in the delivery of specialist dementia care.
- To work in partnership with external consultants in the engagement of customers with end stage dementia to ensure that all are able to have a say.
- To continue with our customer involvement programmes.
- Development of integrated care solutions, where we have multiple service offers.
Chartered Society of Physiotherapy

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

As the professional body for 49,000 chartered physiotherapists the Chartered Society of Physiotherapy (CSP) has, within that membership, a significant group of clinicians who have an expert understanding of this client group and are able to work with them and contribute to pathways of care for clients with dementia and their families and carers.

Under the umbrella of CSP a number of clinical interest groups are responsible for sharing good practice, providing a network for discussion, collecting and promoting the evidence and influencing nationally and locally for policy that enables improved service delivery and patient care. Two groups in particular, Chartered Physiotherapists Working in Mental Health (CPMH) and Chartered Physiotherapists Working with Older People (AGILE), hold a body of knowledge regarding dementia and undertake the above roles. These groups promote best practice regarding the most effective physical and cognitive approaches to dementia care both within the profession and within the health and social care environment.

The CSP together with CPMH have developed comprehensive mental health frameworks, identifying how developing the physiotherapy input into care pathways can support the delivery of integrated care. The frameworks cover England, Scotland and Wales.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

The single biggest challenge is to educate potential referrers for this client group, to ensure that the role of physiotherapy in this field is understood and its value in respect of the outcomes that can be achieved through skilled physiotherapy intervention. Referrers may be GPs, allied health professionals, nurses and other health workers, or may be carers and advocates, or those who commission pathways and services. Often clients with dementia end up in generic services where their specific needs are not properly recognised and where the skilled resources to manage these needs are not present.

The CSP has a specific challenge to address, which is to ensure that physiotherapists working in non-specialist units or services who come into contact with clients with dementia are either trained or have good levels of awareness of the best approaches to use in dementia care.
3. What are your plans as an organisation to respond to these challenges between now and 2014?

• In collaboration with the College of Occupational Therapists, the CSP intends to produce a resource for carers of people with dementia, to support them to identify strategies to manage seating, postural support and the physical management of their family member or client safely and effectively.

• In partnership with CPMH the CSP intends to develop an information resource for referrers and commissioners that will identify why the provision of specialist services for people with dementia is essential particularly with regard to pain management which is frequently misdiagnosed as challenging behaviour.

• The CSP through its many networks will promote to physiotherapists, carers and other professionals the wide range of good practice in the field of physiotherapy and dementia care.

• Resources will be developed to educate carers and health and social care workers in the areas of falls prevention, pain relief, nutrition and promotion of mobility post discharge.

• Resources will be developed to educate physiotherapists who work in generic services about the specialist needs and approaches to the management of dementia.
Counsel and Care

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

Counsel and Care’s role in delivering some of these outcomes would be around our core advice and information service, which helps people with dementia, their families and carers make informed choices and to gain control over the services they receive. The influencing work that we do to improve care and support for older people would contribute to the shaping of services that is needed to achieve the outcomes. Counsel and Care also works with others to deliver research programmes to influence both policy and practice, and our Vital Links befriending network together with our position as a founder member of the Coalition Against Loneliness helps older people, including those with dementia, to build and maintain social networks.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

From our point of view the challenge is around mental capacity and dementia. For many people who contact our advice service this is the key issue of contention. So in delivering the outcomes, we need to ensure that people with dementia and their carers are well informed on the issues around mental capacity and that they are empowered to challenge the system when it is not working for them (see our Care Concerns 2009 report for detail on this as it affects Counsel and Care’s callers).

3. What are your plans as an organisation to respond to these challenges between now and 2014?

Counsel and Care is currently working to a strategy that has six priorities, two of which are influencing the new government to take forward the care funding and reform agenda, and to build a coalition to tackle loneliness amongst older people. We have also been seeking funding for a possible piece of work around mental health and older people in care homes, but have not yet been successful. It would be possible for us to incorporate dementia into all of these pieces of work, ie:

- By ensuring that a funding solution takes into account the burgeoning numbers of people who will be living with dementia by 2014 and beyond.
- How befriending and other solutions to loneliness can include people with dementia and their carers.
- Should we be successful in obtaining funding, our project on mental health in care homes could consider dementia alongside other conditions that affect younger people as well such as depression – often these conditions are mistaken for dementia in older people, so we need to clarify the differences and also talk about early onset dementia with people in their 50s.
Dementia Services Development Centre

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

The Dementia Services Development Centre with its offices in Belfast, London and Scotland has a role in improving services for people with dementia and their carers. We will do this by providing information through our free library and information service which is accessed by people online across the UK. We will also continue to provide training for people who work in the field, at low cost or free, through training the trainers and online material, as well as directly delivering training. We’ll help people design dementia-friendly buildings and provide books and learning materials on design and dementia, including free downloads from our website. We will provide degree level dementia education, and undertake research in how to make things better for people with dementia and their carers. In all of this we will be guided by people with dementia and their carers, and those who work in the field, who have the job of implementing government policy.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

One of our key challenges is that people think we are Scottish! Well of course we are. But with our offices now in London and Belfast, we signal that we understand the challenges around the UK. With our partnerships across the globe, we are confident that we can bring the best of international knowledge together in one place. A challenge that remains is that we are non profit and supported by a charity. This means that we are limited in what we do by funds. Even with our low prices, people indicate that they can’t afford to pay for training or books. It’s a false economy for them, because doing things badly and in outdated ways costs more than doing them properly.

3. What are your plans as an organisation to respond to these challenges between now and 2014?

• We will expand our team and our range of services to match the need of providers.
• We will increase our research input to the courses and books that we provide.
• We will increasingly provide our services free at the point of delivery by finding new funding models.
• We will rely increasingly on electronic communication, for example building on our free online library.
I. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

Craegmoor considers the preservation of autonomy, personal choice and control a priority when supporting a person living with dementia. People living in our homes are encouraged to become involved in the delivery of their care, everyday decisions right through to influencing company policy and procedure through the Craegmoor initiative Your Voice.

To help care staff understand dementia and its impact on individuals, Craegmoor has invested in a career development framework. The framework provides mandatory training in well-being of the older person and person-centred care through to university led course for managers. The purpose of the framework is to raise the level of awareness and knowledge at all levels of care delivery along with identifying people to lead dementia care in each home.

Craegmoor has worked with a number of organisations to develop a range of physical environments that enable individuals living in our homes to lead as independent a life as possible and promote a sense of well-being.

Craegmoor’s Older People Division is working with the Association of Dementia Studies at the University of Worcester to support research projects and training initiatives with the aim of improving the lives of people living with dementia.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

The lack of a monitored and enforceable national standard for the delivery of care for a person living with dementia. For a national company this can create confusion when you are working with a number of commissioning authorities who may have all adopted different frameworks, expectations and measures. Different interpretations and emphasis of the National Dementia Strategy along with a lack of a training standard contributes to this challenge.

Consistency of staff groups presents one of the biggest challenges to delivering a high standard of care. Traditionally care work is seen as a ‘menial’, unskilled work and the workforce is often transient. Working with and caring for people living with dementia requires a lot of skill and dedication, which care staff are often unprepared for.
3. What are your plans as an organisation to respond to these challenges between now and 2014?

- Craegmoor has a three year Dementia Care Strategy detailing actions and expectations for dementia care within the company.
- There is a dedicated lead for the Dementia Care Strategy, who also provides advice and support for individual services.
- There is a team of Quality Development Support Managers who visit each home regularly to support care delivery and audit key areas of care.
- Craegmoor is investing in a range of staff training to support best practice in the delivery of dementia care, establishing a leader in dementia care in every specialised service.
- Craegmoor works closely with people living in our services, their families and friends to develop and support the way in which care is delivered. People are encouraged to become involved in decisions that affect them at a service and company level. The initiative Your Voice enables people’s opinions to be heard throughout Craegmoor, through individual interactions, comment cards, meetings at home, regional and national levels and annual questionnaires.
- Craegmoor is developing a network of Dignity Champions to promote dignity and respect in every aspect of care delivery. The network will be supported by regional workshops to share best practice and key challenges.
- As a company we aim to increase our work with friends and families, supporting people to understand the rights of people living with dementia, our philosophy of care and the effects of dementia.
- Craegmoor works in collaboration with learning bodies, in particular participating in research and developing training.
1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

The Department of Health’s work centres around three strategic objectives – better health and well-being for all, better care for all and better value for all. In relation to dementia, this means ensuring that public funds are used efficiently and effectively to provide health and social care services which meet the needs of people with dementia and their carers.

The Department published its revised, outcomes-focused implementation plan for Living Well with Dementia – A National Dementia Strategy on 28 September 2010. The implementation plan sets out the Department’s priority objectives for securing improvements in dementia care, which are:

- Good-quality early diagnosis and intervention for all.
- Improved quality of care in general hospitals.
- Living well with dementia in care homes.
- Reduced use of anti-psychotic medication.

The implementation plan also sets out for health and social care localities and their delivery partners:

- The Department of Health’s role and priorities during 2010/11 for supporting local delivery of and local accountability for the implementation of the National Dementia Strategy.
- The Strategy’s fit with the new vision for the future of health and social care set out in the White Paper Equity and Excellence: Liberating the NHS.
- The fit with the consultation document Liberating the NHS: Transparency in outcomes – a framework for the NHS.

The Department, in conjunction with the National End of Life Care Programme, is working with and supporting key partners such as the National Council for Palliative Care and national dementia charities to help improve end of life care for all adults, including those with dementia.

The Department also has a key role in influencing the public, communities and organisations in both the private and voluntary sectors to be more supportive of people with dementia and their carers.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

A key challenge for the Department of Health, in the current economic climate, is to deliver more efficiently and effectively using the resources available and to support NHS and social care to do the same. £8.2 billion is already spent on dementia by the NHS and social care and there is potential to identify savings that could be used to deliver new services for people with dementia.

A second key challenge is to encourage and support localities to prioritise implementation of the National Dementia Strategy. The revised NHS Operating Framework for 2010/11 issued on 22 June 2010 confirmed dementia as a key area for local prioritisation. The Framework states that people with dementia and their families need information that helps them understand their local services and the level of quality and outcomes that they can expect, and that localities should publish how they are implementing the Strategy to increase local accountability for prioritisation.

The government has commissioned a national audit of dementia services, which is establishing the provision of dementia services across the country. The audit will provide local NHS and social care organisations with a measure of their progress in key areas including the use of senior clinical leads for dementia in hospitals, establishment of memory services, reducing the use of anti-psychotic medication and expenditure on dementia services, so that they can drive forward action to accelerate improvements in dementia care. The initial results are expected by the end of the year.
3. What are your plans as an organisation to respond to these challenges between now and 2014?

In line with the Department of Health’s new role, which is more enabling and less directive, the Department has identified the key enablers for change set out below. These are aimed at supporting local delivery of and local accountability for achieving quality outcomes in dementia care.

• Work in consultation with partner organisations to identify key outcomes which people with dementia and their carers expect. This work will feed into the consultation on Transparency in outcomes – a framework for the NHS1 and the Department’s ‘zero-based review’ of social care data collection.

• The appointment of Professor Alistair Burns as the first National Clinical Director for Dementia to promote clinical and professional engagement in the design and management of services.

• The NHS National Quality Board is looking at the dementia care pathway and ways to support improved commissioning, workforce capability and better quality data.

• The National Institute for Health and Clinical Excellence (NICE) Quality Standards in Dementia Care were launched in June 2010. The Department is working with NICE and the National Quality Board to ensure harmonisation of the Standards with the National Dementia Strategy.

• The appointment of three National Dementia Champions for the NHS, the independent sector and social care, who will:
  – Provide leadership at local level.
  – Encourage and embed delivery at all levels.
  – Support local accountability.

• Reducing the use of antipsychotic medication – the National Clinical Director for Dementia is leading the work to implement the recommendations in the report into the over-prescribing of anti-psychotic medication2, with the support of an Advisory Group.

• The revised NHS Operating Framework for 2010/11 highlights that the NHS and its partners must give a greater priority to dementia. Local organisations will be expected to publish how they are delivering on quality outcomes so that they can be held to account by local people.

• Developing a comprehensive commissioning pack to support local commissioners to deliver improved services for people with dementia.

• The establishment of a Workforce Advisory Group, chaired by the National Clinical Director, to deliver objective 13 of the Strategy – an informed and effective workforce for people with dementia.

• The Department provides substantial funding for health research, through the National Institute for Health Research (NIHR) and the Policy Research Programme (PRP), which is available to support high quality research in all areas of health science, including dementia.

• A time-limited Ministerial Advisory Group on Dementia Research (MAGDR) has been established, bringing together the main bodies with an interest in dementia research. The aim of the Group is to suggest ways to increase the volume, quality and impact of dementia research.

• Support for a Demonstrator Site Programme to test models of delivery for the role of dementia adviser and for peer support networks.

• A National Audit of Dementia Services commissioned from the NHS Information Centre. The initial audit findings are expected to be available in autumn 2010 and will help local areas to prioritise areas for action.

• Development of a Good Practice Compendium, which is accessible online via the Dementia Information Portal, aimed at bringing together examples in improving dementia care from across the regions.

• A resource guide on end of life care for people with dementia has been produced for health and social care professionals which provides links to information sources, resources and good practice.3

1. Transparency in outcomes – a framework for the NHS, Department of Health, July 2010
2. The use of antipsychotic medication for people with dementia: Time for action – A report for the Minister of State for Care Services, Professor Sube Banerjee, 12 November 2009
English Community Care Association

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

The English Community Care Association (ECCA) is a national representative body with over 5,200 Care Services in membership. We will raise the profile of the dementia strategy with our members and we will encourage and support them to develop and deliver their own dementia action plans. If all ECCA members develop and deliver better services for people with dementia this will have a positive impact on over half a million people with dementia and their carers.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

There are several major challenges to delivering improved services for people with dementia. These include:
- Poor commissioning.
- Lack of engagement by primary healthcare.
- Lack of specialist care staff and specialist care service managers.
- High staff turnover.
- Low staff to person with dementia ratios.
- No coherent training and career pathway.
- Over prescription of anti-psychotic medication.

3. What are your plans as an organisation to respond to these challenges between now and 2014?

In order to address these issues ECCA will between 2010 and 2014 do the following:
- Have a focused awareness campaign with ECCA members and other care providers on the objectives of the National Dementia Strategy.
- Develop an innovation exchange with Social Care Institute for Excellence to identify and cascade examples of good practice in dementia care.
- Work with the British Geriatric Society to develop a model of good practice for primary care services to care homes.
- Develop links to the regulator Care Quality Commission to inform their regulatory role in ensuring this model is delivered.
- Develop with the Skills Academy for Social Care a leadership programme for dementia care services.
- Develop a resource with SCIE to identify ways of managing challenging behaviour and reducing the use anti-psychotics.
- Work with the Gold Standards Framework (GSF) team to train staff to use the GSF end of life care pathway for people with dementia who end their lives in care services.
- Sponsor an award at the Great British Care Awards for Excellence in Dementia Care.
Local Government Group

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

The Local Government Group (LGG) will work with ADASS (Association of Directors of Adult Social Services) to ensure that councils continue to prioritise the needs of people with dementia and their carers. We will pay particular attention to dementia services in the changes to commissioning that will follow the NHS White Paper:

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

The LGG has a particular responsibility to support the political leadership of adult social care. We will pay particular attention to simple messages for lead members about the Strategy and its implications for commissioning and service development.

3. What are your plans as an organisation to respond to these challenges between now and 2014?

We will:

- Organise a presentation to the Community Wellbeing Board and provide regular updates.
- Develop briefings for lead members and provide opportunities for discussions at our regional lead member networks.
- Consider opportunities for workshops at the National Children and Adults Conference each year.
- Consider developing a conference in the LGG programme at an appropriate moment.
- Assist in promoting material for councils through website and newsletters.
I. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

Within Four Seasons Health Care (England Division) we have 140 units or homes that provide care for people living with dementia, equating to approximately 3,800 beds.

In January 2008 we developed our own accreditation scheme, comprising 144 criteria to help homes develop into centres of excellence for people living with dementia. The PEARL (Positively Enriching And enhancing Residents Lives) programme consists of training, mentorship and support to work in collaboration with the home to help them achieve at least 65 per cent of Score 5s (Bronze Award). Four Seasons Health Care have their own dedicated Dementia Care Team of eight people who work across the UK to provide help and support to our residents who are living with dementia. We currently have 33 units within the company that have achieved PEARL status. It takes approximately 12 months for each home to achieve PEARL and we estimate that we should have all homes through by the end of 2014.

The team has won two awards for the work we have been doing (Guy Rotherham and Excellence Network) as in the first phase of the project there was a 52 per cent reduction in anti-psychotic medication on average across the care homes that were validated. We are now measuring other clinical indicators within Phase 2 of the project and have noted many successful outcomes for individuals including weight gain, reduction in both falls and distressed reactions.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

We occasionally experience difficulties explaining the concept of person-centred approaches to relatives or carers of people living within our homes. For example if a wife tell us that she would like her husband shaved every day but he becomes so distressed in a morning that we shave the gentleman in the afternoon when he is happy for us to do so. Also a critical part of our work is obtaining life story information but relatives or carers sometimes do not appreciate why this is important, despite explanation. As more organisations become person-centred (including general hospital, domiciliary care), hopefully this will reduce.

We occasionally experience difficulty also when we are trying to work with GPs/consultants to titrate or discontinue anti-psychotic medication as the relative/carer becomes anxious that the person will become distressed, particularly if they have been on the medication for a number of years.

Again, hopefully as public awareness is raised these encounters will become less frequent and also as we publish our own successful outcomes with PEARL, relative and carer confidence will increase.
3. What are your plans as an organisation to respond to these challenges between now and 2014?

• All dementia care units/homes to be validated as PEARL homes by 2014.

• Continue to use DCM (Dementia Care Mapping – a specialised observational assessment tool) to establish the views of the person living with dementia and to help train our staff in person centred approaches.

• To continue to provide two-day person-centred care training to all our dementia care units/homes.

• To review the PEARL criteria each year to ensure that it is aligned to latest government recommendations ie National Dementia Strategy, NICE guidelines and outcomes and also that it contains recommendations in relation to very latest evidence/research based practice.

• To continue to review our Dementia Care Manual annually in line with the PEARL criteria review (as policies/guidance are aligned to the PEARL programme).

• To continue to listen to our residents, our relatives and our staff and to act on suggestions for improvements.

• To continue to update the knowledge of the Dementia Care Team to enable our staff within the company to share our knowledge.

• To continue to work towards our Dementia Care Vision and help all our staff working within our homes to recognise that each person living with dementia is unique.
Housing and Dementia Research Consortium

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

The Housing and Dementia Research Consortium (HDRC) is a membership group comprising 85 providers, commissioners and other organisations and individuals who have come together to achieve robust research into housing with care for people with dementia (also known as Extra Care or very sheltered housing). HDRC’s core founder members are four well-established providers of housing with care: Housing 21, Anchor, Hanover Housing Association and MHA. Housing with care has the potential to deliver all the outcomes listed in the Dementia Declaration, but is more likely to do so if evidence is available of what works best for people with dementia living in housing with care, or making use of its facilities. Housing with care is a relatively new concept, with distinctive features, and so far; only a small amount of research has been undertaken to provide this evidence. HDRC’s aims therefore are to:

- Shape the agenda of research into housing with care to ensure its relevance and usefulness to housing providers and people with dementia.
- Work together to have greater weight when applying for research funding.
- Deliver more ambitious large-scale, multi-site, multi-provider research.
- Disseminate findings from research and evaluations to influence policy and improve practice.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

The main challenge for HDRC is undoubtedly funding. Some research findings from other settings are transferrable to housing with care, but its distinctive features necessitate specific research as well while its many variations make generalisations from small-scale, single-provider or single-unit studies difficult. Thus large scale, multi-site research is needed. With approximately 43,000 dwellings in England in March 2009, housing with care is an increasingly popular option for older people with support needs, and occupants with dementia deserve the best chance of the Declaration’s outcomes being achieved. The challenge then for HDRC is to raise the profile of housing with care for people with dementia as an important area of research, worthy of investment. Further challenges for HDRC include designing research with its partners which validly answer key questions in a complex area, ensuring proper engagement of those affected by dementia; and keeping the momentum going and its membership engaged within the context of limited resources.
3. **What are your plans as an organisation to respond to these challenges between now and 2014?**

The four founder members have contributed to a fund to employ someone part-time until the end of this financial year (end March 2010) to move the agenda forward. It is hoped that a successful research bid would include funding this role in the longer term. The core group will review the position at the beginning of 2011. The role of the research co-ordinator is to:

- Develop the research agenda.
- Make links with research partners.
- Find funding.
- Prepare research proposals with research partners – one bid has recently been submitted.
- Develop a website.
- Use opportunities to raise awareness and understanding of housing with care and the need for research, in the context of people with dementia.
- Link with the membership, providing updates and any other information likely to be of use to them.
- Continue to link with the Housing Learning and Improvement network.

In any successful research bid, the HDRC will:

- Identify suitable research sites.
- Be an active partner in shaping the research methodology.
- Ensure that researchers have a proper understanding of the housing with care setting.
- Ensure that people with dementia and their carers are properly and ethically involved.
- Use its networks to disseminate research findings and encourage implementation in practice.

The long-term future of the consortium will depend on its success in fulfilling its aims and becoming self-financing.
Jewish Care

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

Jewish Care is committed to achieving better outcomes for people with dementia and their carers through our commitment to excellence in our frontline services. These include:
• Advice and support line.
• Community support and advocacy.
• Carers support.
• Home care.
• Community centres.
• Dementia day centres.
• Residential and nursing homes.
• Independent living/extra care.
• Respite care.
• A dedicated disability and dementia team to provide education and guidance to Jewish Care colleagues working with people with dementia, and to the Jewish community.

All of our services serve Jewish people in London and the South East and we strive to work with person-centred values. The person, their unique history and individual rights to choice and control within the services we offer, are the primary focuses of our work. Jewish Care’s values (enabling, caring, integrity, excellence and inclusive), reflect and support the outcomes outlined in this declaration. We are committed to working closely with primary care trusts, local authorities and other agencies to ensure multi-disciplinary co-operation for the achievement of best outcomes. We collaborate with Alzheimer’s Society, Dementia UK, Skills for Care, Social Care Institute for Excellence, Bradford Dementia Group, University College London, the King’s Fund, other learning and development agencies and for creative arts projects The Wigmore Hall – Music for Life.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

Jewish Care identifies the following key challenges to delivering for people with dementia:
• We need to lobby for appropriate funding for all services in order to deliver standards of delivery that can ensure the declaration’s outcomes are achieved for people with dementia who are our service users.
• Advocating on behalf of people with dementia so that they have real alternatives, for example being sufficiently supported to live in their own homes or the choice to move into high quality residential care or extra care/independent living accommodation.
• Educating the work force (paid and unpaid) through the Qualifications and Credit Framework (QCF) pathways, continued support from the in-house dementia specialists and access to e-learning resources.
• Respite care: Our challenge is to fully understand the needs behind people’s requests for respite places and to provide facilities that match people’s requirements.
• End of life: We recognise the challenge to be able to provide end of life care for people with dementia who are residents in our homes.
• Upgrading and building residential and nursing accommodation to best dementia design and guidelines.
• Ensuring access for clients to empowering assistive technologies.
• Identifying the needs and demand for services for younger people with dementia in the Jewish community.
3. **What are your plans as an organisation to respond to these challenges between now and 2014?**

**Funding**

Jewish Care will continue to lobby for appropriate funding to provide relevant and high standard services to people with dementia and their carers. Whenever possible we will endeavour to lobby politicians, at local and national levels, and commissioners that good dementia care requires and is given a realistic budget. In accordance with the personalisation agenda, we will endeavour to educate people on the true cost of high quality dementia services. Jewish Care’s campaign and fundraising department will continue to highlight services for people with dementia as a high priority with potential funders and benefactors.

**Advocating on behalf of people with dementia**

Jewish Care commits to:

- Ensuring people with dementia and their carers have access to a skilled workforce, in a wide range of services, that are knowledgeable about dementia and can offer flexible approaches to individual challenges.
- Continuing and developing a team of Dementia Care Champions in residential and nursing homes supported by senior leads for dementia who take on the role of Champion’s mentors. Champions will use the VIPS framework to promote and measure high quality services (from now to 2014 and beyond).
- The establishment of Dementia Care Champions for day and home care services (establish by June 2011).
- Continuing Dementia Care Mapping (DCM) in dementia services.

**Educating the work force**

All paid and unpaid staff will continue to access induction and ongoing training provided by Jewish Care’s specialist Disabilities and Dementia Service. With the availability of the QCF dementia pathways from October 2011 Jewish Care undertakes to support staff working with people with dementia to achieve these qualifications. (2010 – Develop routes of access to QCF dementia units for all Jewish Care staff working with people with dementia and from 2011 to 2014 to support and monitor the achievement of these qualifications.)

**Respite care**

Jewish Care will continue to offer respite care to people with dementia. We will develop a clear policy on respite care by the end of 2011.

**End of life care for people with dementia**

All of Jewish Care’s residential and nursing homes will all be registered with the Gold Standards Framework by the end of 2011. Jewish Care is currently working with University College London and The King’s Fund on research into end of life care for people with dementia. The findings of this research will be published in 2011.

**Upgrading and building residential and nursing accommodation**

In September 2010 Jewish Care opened a new dementia care nursing and residential home. The home’s built environment follows the latest dementia specifications. A programme of refurbishment and building is currently under review for existing and planned new buildings.

**Assistive technologies**

In October 2010 Jewish Care will establish an Assistive Technologies Committee to monitor development in this area for people with dementia and to advocate for clients to have access to them.

**Younger people with dementia in the Jewish community**

Throughout 2011 Jewish Care’s Community Support Service and Advice and Support Service will gather data about younger people with dementia in the Jewish community. This information will be used to develop a plan of action for future years.
The Mental Health Foundation is a research and development charity so our role is to carry out research into how better outcomes can be delivered for people with dementia and their carers, and to disseminate these as practical solutions and recommendations for policy makers, service providers and practitioners. We do this through the reports and guidance we produce, our policy and public affairs work and responses to government consultations, and the information we provide to print and broadcast media. Recent examples of this have been producing the reports Dementia – Out of the shadows and My name is not dementia for Alzheimer's Society. We also carry out service improvement projects in collaboration with service providers to develop new and innovative ways of delivering dementia care. These currently include Dementia Choices, a project about personalisation and dementia, and Home Improvements, a grant-making scheme for projects aimed at benefiting people with dementia living in care homes. In all our work we seek to actively involve people with dementia, their families and their carers and we also produce information in the form of booklets and via our website about dementia aimed at these groups.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

The main challenges from our perspective are the current public spending restraints, especially among local authorities, and limited resources for research (especially when compared to other illnesses and diseases), at a time when the numbers of people with dementia are increasing rapidly. We have concerns that these restraints will have a detrimental impact on the ability to properly implement the National Dementia Strategy and are also concerned that the prioritisation of outcomes focused on primary care, general hospital care, care homes and anti-psychotic prescribing will be to the detriment of other important outcomes, especially social care and community support. We also believe there is an inadequate public and sometimes professional understanding of dementia issues, and this is exacerbated by the stigma attached to a diagnosis of dementia.
3. What are your plans as an organisation to respond to these challenges between now and 2014?

• Completion of the Dementia Choices project in 2011. This will produce a range of information and guidance aimed at people with dementia, their families and staff working in social care to support and promote the use of self directed support (eg personal budgets) for people with dementia. These will be available in April 2011 and we plan to disseminate them through our media and communications networks and through a national event and regional events.

• Completion of the Home Improvements grant making scheme in 2011–12. This scheme has funded four innovative service improvement projects aimed at benefitting people with dementia in care homes. All the projects will be producing project reports and we plan to produce a report for the whole scheme which we would disseminate through our media and communications networks and possibly a national event.

• Updating our information booklets on dementia for people with dementia, family carers, and children and young people.

• Ensuring that issues affecting people with dementia are included in our ongoing project work on mental capacity issues.

• Ensuring that people with dementia are included, as appropriate, in our ongoing project work on promoting positive mental health and well-being for the general population, as well as projects tackling more specific mental health issues (eg depression).

• Seeking funding for further research into quality of life issues for people with dementia (especially those with more severe dementia living in care homes), and self-help/peer support for people with dementia living in community housing.

• Working with other organisations, as appropriate, and people with dementia, to ensure their voices are heard in policy development, service improvements, and other initiatives affecting their lives, at both a national and regional level.

• Ongoing policy work to ensuring that dementia is firmly placed within the Department of Health’s mental health strategy and public health strategy due out from the government end of 2010/beginning of 2011.
MHA

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

MHA provides services for older people throughout the UK offering a wide choice of support at home, housing and care homes. Our services are specifically designed for people with dementia and offer a person-centred approach to care and support which stresses the uniqueness of each individual and our commitment to dignity, choice and fulfilment, as well as meeting physical, social and spiritual needs.

We aim that people we serve have as much control over their lives as possible and the same rights as anyone to choices and decision-making in where and how they live, their daily lives and the care and support they receive.

Our housing schemes and care homes are designed to provide familiar and homely surroundings with ease of access, orientation and safety with maximum freedom of movement. We incorporate technology to assist with care and health monitoring, safety and comfort with the minimum of intrusion.

We aim to offer services of a high standard which provide examples of good practice, and to develop new services which enhance the choices available to people with dementia and their families.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

- Most local authorities provide little or no additional funding for older people who have dementia compared with those who do not. We believe building design/layout is important and should attract additional funding. The NHS nursing care contribution is also not available for people with dementia, despite the fact that staffing levels in specialist homes are the same for nursing and dementia.

- We believe purpose built apartments and/or bungalows on a site with 24 hour care and support is a service potentially useful for many people and under-provided in the UK. Clarification from regulators that such services are not to be regarded as care homes would promote additional services.

- There is very little research, or funding for research, into the care and support needs of people with dementia.
3. What are your plans as an organisation to respond to these challenges between now and 2014?

- We will be continuing to seek opportunities for the development of new specialist care homes, particularly in urban and deprived areas.

- We are developing, through conversion of our existing sheltered housing schemes, and new-build, new housing with care services to include specialist dementia care.

- We are developing more community services for people with dementia including personal care, dementia day care, carers’ support groups, befriending, signposting and regular contact, especially where we can link this with existing or new care homes and schemes nearby to enable sharing of resources and staffing, and maximise the use of volunteers.

- Our dementia training strategy will include local dementia champions, new e-learning and other induction training in dementia awareness for all staff, training resource packs and targeted training for care staff, both in specialist and general care settings.

- We are committed to research into care and support for people with dementia, including into pioneering work with music and reflexology therapies, and will initiate and participate in research with academic, funding and provider partners, including through the Housing and Dementia Research Consortium (HDRC).

- We will be developing more opportunities to raise awareness of our services locally with resource libraries in homes and schemes, holding public events and sending out ‘signposting’ newsletters.

- We will work closely with local healthcare colleagues to give people as much information and support as possible, using single assessment processes where available, easier access, shared resources and a joint approach to high quality end of life care.
1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

The National Council for Palliative Care (NCPC) is the leading umbrella charity for all those involved in palliative and end of life care. Supporting people with dementia and their carers to have access to high-quality personalised care that meets their individual needs and preferences until they die is a priority role for us.

NCPC is at the forefront of ensuring that dementia and end of life care work in partnership. It is our role to keep supporting greater integration between the two. Our expert group on dementia provides a unique and powerful combination of expertise from dementia organisations (including Alzheimer’s Society and Dementia UK), the care home and housing sector (including Anchor Trust, Bupa and the National Care Forum) and palliative care services. It produces influential publications and training to support development of services responsive to the needs of people with dementia approaching the end of life.

NCPC is also leading the national Dying Matters coalition to raise public awareness and equip people to talk about and plan for their end of life and support a good death. Early planning is particularly important for people with dementia and their families to help them make informed choices. Through information and support, Dying Matters is helping local communities and professionals have the skills to do this effectively.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

There is a growing recognition of the need for palliative and end of life care to work in partnership with dementia care. However, increased training of both dementia staff and palliative care staff is vital. Training on end of life care in dementia must be integral to curricula for all professionals working with people with dementia and their families. The rapidly growing numbers of people with dementia and the anticipated rises in death rates will increase the demand for services. At present, between 60 and 70 per cent of people want to die at home but most people die in hospital. Reversing this trend for people with dementia is a particular challenge. It needs early communication and planning for people’s preferences and needs to be identified and met. Likewise, community and home based services need to be strengthened to respond to the demand.
3. What are your plans as an organisation to respond to these challenges between now and 2014?

- Working with our expert group on dementia, we will continue to lobby for greater integration of palliative and end of life care with dementia. We will continue to produce publications and training resources.

- We will hold a national conference on dementia and end of life care, Achieving a Good Death with Dementia, on 8 December 2010.

- Develop accredited training with Alzheimer’s Society based on NCPC’s Care to Learn Resource Pack and Dementia Module.

- Continue to work in Hertfordshire to support integrated pathways for palliative and dementia care locally, as part of our role to turn policy into practice.

- Seek to develop communications guide to help professionals talk about end of life care issues with people with dementia and their families. This work would be led by the experiences of people with dementia and their carers, and build on our successful communication guide for COPD and end of life care.

- Continue to work with care homes and housing organisations to support them in their delivery of end of life care for their clients, including people with dementia.

- Build on our work to date on personalisation and end of life care to consider practical approaches to personalising services for people with dementia approaching the end of life.

- With the Dying Matters coalition, develop further information and resources to support people to be confident in discussing their end of life care preferences. This will include work to support all staff to improve their own confidence so they are better able to discuss these sensitive issues with those they care for, and families and carers.
NHS Alliance

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

The NHS Alliance is the only organisation that brings together primary care trusts with practices, clinicians with managers and board members – and NHS primary care with its patients.

It is completely independent of government (and of any particular interest group or political party too) though it is happy to work in partnership with all bodies associated with the NHS providing its values and principles are not compromised.

The NHS Alliance membership and its hardworking national executive is fully multi-professional. No other NHS body has primary care trust chief executives and other senior managers, doctors and practice managers, nurses, pharmacists and allied health professionals, along with board chairs and members, all working together to improve the health service.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

The NHS Alliance champions, supports and represents NHS primary care and all those working in it as a movement committed to a fair and progressive NHS that is free from the traditional tribalism of single interest groups. At the same time, it recognises the value of specialist expertise and its thirteen professional networks allow all groups to benefit from their insights, ideas and experience.

3. What are your plans as an organisation to respond to these challenges between now and 2014?

• NHS Alliance will work through commissioners and providers to improve commissioning of local dementia services and explore good models of integrated provision.

• We hope to launch a conference on the commissioning of dementia services next year and provide educational opportunities for GPs and nurses wanting to improve their dementia services locally.

• Through our GP Consortia Federation, we will also explore ways in which GP commissioning consortia and local authorities can work more proactively and in a more integrated manner to improve local dementia services.
NHS Confederation

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

The NHS Confederation, as an organisation representing leaders in the NHS, will work to ensure our members have support to understand and deliver their role in delivering the outcomes for people with dementia and their carers.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

Commissioners and providers of health care are working in challenging times, due to the need to deliver the major structural changes proposed in the health care white paper and make £15–20 billion of efficiency savings at the same time.

We will need to provide straightforward, clear messages to enable commissioners and providers to maintain the focus on the transformation of services for both patients and carers of those with dementia, and that they continue to improve in line with the national strategy.

3. What are your plans as an organisation to respond to these challenges between now and 2014?

We plan to:

- Arrange seminars on dementia and associated topics (eg Ambulance Service Network event in December 2010).
- Consider including a session on dementia at our annual conference and exhibition in 2011.
- Update our website to provide signposting and supportive material for our members relating to the dementia declaration.
- Promote appropriate material to our members via electronic newsletters.
I. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

The National Institute for Health and Clinical Excellence (NICE) provides national guidance on the promotion of good health and the prevention and treatment of ill health. Our main contribution to better outcomes for people with dementia and their carers is through the 2006 clinical guideline, Dementia: supporting people with dementia and their carers in health and social care, jointly produced with the Social Care Institute for Excellence (SCIE), the 2006 technology appraisal, Donepezil, galantamine, rivastigmine (review) and memantine for the treatment of Alzheimer's disease (amended in 2007 and 2009), and the dementia quality standard of June 2010.

The guidance and the quality standard on dementia reflect the widely accepted principles of person-centred care that underpin good practice in the field of dementia care.

Versions of the guidance for patients and carers aim to help them play an active role in decisions about treatments and services for dementia.

We support local implementation of this guidance and the dementia quality standard by providing a range of implementation tools for commissioners and health and social care providers and professionals.

The guidance and the quality standard also provide criteria for local monitoring and management of performance and for national reviews and studies of the quality and value for money of dementia services.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

Priorities for implementation in the NICE/SCIE clinical guideline aim to meet key challenges to delivering outcomes by ensuring that:

- People with dementia are not excluded from any services because of their diagnosis, age, or coexisting learning disabilities.
- Professionals seek valid consent from people with dementia.
- Carers receive an assessment of need and, if appropriate, psychological therapy.
- There is coordination and integration of health and social care.
- Memory assessment services are the single point of referral for all people with a possible diagnosis of dementia.
- Structural imaging is used in diagnosing dementia.
- People with dementia who develop challenging behaviour are offered an assessment, and a tailored care plan if necessary.
- There dementia-care training for all staff working with older people.
- Acute and general hospitals address the personal and social care needs and the mental and physical health of people with dementia.
3. What are your plans as an organisation to respond to these challenges between now and 2014?

• The dementia quality standard: this is likely to be the most significant contribution from NICE in responding to these challenges over the next few years. This is because of the role defined for NICE quality standards in the NHS outcomes framework proposed in the recent white paper, *Equity and excellence: liberating the NHS*. It is clear that the NHS outcomes framework will include outcomes expected by people with dementia and their carers. NICE expects to support the development of the NHS outcomes framework.

• Support for implementation of the dementia quality standard: for example, dissemination of resources: patient information; cost impact and commissioning assessment; guide to commissioning a memory assessment service; and audit support.

• The shared learning database: a section of NICE’s website enabling searches for examples of implementing NICE guidance and overcoming barriers to implementation, including guidance on dementia – see www.nice.org.uk/sharedlearning

• Collation of reports on implementation of NICE guidance: the ERNIE database (Evaluation and Review of NICE Implementation Evidence) enables searches for published reports on the uptake of NICE guidance, including dementia-related guidance – see www.nice.org.uk/ernie/

• Support for national studies and reviews: for example, those by organisations such as the Care Quality Commission and the National Audit Office which use NICE guidance or NICE quality standards to define study or review criteria.

• Review of the NICE/SCIE clinical guideline on dementia: consideration in November 2011 of the need to update the guideline.

• NHS Evidence: this a web based service that ensures that professionals in health and social care have free access to the quality-assured, best-practice information required to inform evidence-based decision making. NHS Evidence provides up-to-date information on research findings, evidence, and policy on dementia. For example, it provides an annual evidence update on Alzheimer’s disease and dementia – see www.library.nhs.uk/laterlife/
1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

The revised Dementia Strategy Implementation Plan (Quality outcomes for people with dementia: building on the work of the National Dementia Strategy, Department of Health 2010) prioritises four areas for quality improvements in dementia care. Primary care, and GPs, have key involvement in three of these:

1. Good quality diagnosis and intervention.
2. Living well in care homes.
3. Reduction of antipsychotic drugs in dementia.

The Royal College of GPs’ (RCGP’s) role will be focused on these three areas, initially at a national level, through the work of the RCGP champion for Ageing/Older People (Professor Louise Robinson). Professor Robinson is already working collaboratively with the Department of Health National Dementia Strategy (via the Workforce Development Group and the National Implementation Board), British Geriatrics Society Older Peoples Forum and Alzheimer’s Society.

In addition, she is the primary care lead, representing the RCGP, on the Ministerial Advisory Group on Dementia which is led by the national dementia lead Professor Alistair Burns. This group is facilitating work on priorities 1 and 3.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

The main challenge is that the above actions/outcomes are currently led by a named individual representing the college as one of their clinical champions. The RCGP clinical champion initiative, whereby a named GP represents the college in their particular clinical area, is due to end in 2011, with Professor Robinson’s role as Clinical Champion for Ageing and Older People due to finish in December 2011.

From 2012 to 2014, the RCGP would need to identify an individual/college representative to lead and take over the role of leading on the National Dementia Declaration Action Plan.

Additional challenges are around the core training of GPs and ensuring that the GP curriculum meets the needs of an increasingly ageing population with GPs sufficiently skilled to care for both people with dementia and older people in general. Dementia is just one health challenge presented by an ageing population, GPs need to recognise this and that people with dementia have physical as well as mental health needs. Currently only about one third of GPs will choose to include care of older people as a part of their compulsory core training; the college may need to consider if this is sufficient for a twenty first century GP and their population.
3. What are your plans as an organisation to respond to these challenges between now and 2014?

The RCGP’s role will be focused on the three areas outlined, initially at a national level, through the work of the RCGP champion for Ageing/Older People (Professor Louise Robinson) via:

1. Ministerial Advisory Group for Dementia, led by Professor Alistair Burns the national dementia lead. This group has selected primary care as a key area for intervention and early diagnosis by GPs as a priority area through dissemination of educational initiatives and promotion of GP-friendly cognitive assessment tools.

2. British Geriatrics Society Care Homes project: Professor Robinson is RCGP representative on this (completion 2011). Outcomes include: guidance for GPs for improved health care in care homes and advice to GP commissioners on models for better quality health care.

3. A national advisory group on anti-psychotic prescribing (Professor Robinson; primary care lead for RCGP). This group will be facilitating a national primary care audit; identifying local models of good practice and developing national guidance.

Specific outcomes thus identified will be achieved by 2012 and will include:

- A range of educational resources focused on dementia that are available to both RCGP members through the college, but also to all NHS GPs via sources such as the Department of Health Dementia Information Portal.
- Cognitive assessment tools that are acceptable and user friendly to GPs.
- Guidance for GPs on the provision of better health care in care homes.
- Identifying models of good practice on the reduction of anti-psychotic drug prescribing in primary care.
- National guidance, developed in collaboration with other relevant colleges ie Royal College of Psychiatrists, on the prescribing of anti-psychotic drugs in dementia.

Additional outcomes may be identified by the RCGP.
I. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

The Royal College of Nursing (RCN) fully supports the principles embraced within the National Dementia Declaration in achieving better outcomes for people with dementia and their carers. The need to improve the experience of those affected by dementia is clear and we believe that nurses have a significant role in supporting this agenda.

The RCN is keen to work collaboratively with a range of professional and voluntary organisations involved in the delivery of care for people with dementia and their carers. We would like to see a co-ordinated approach to sharing resources, good practice and developing ways forward to supporting the desired outcomes.

As a member organisation of over 400,000 nurses and health care assistants we will promote awareness of needs, disseminate resources and work towards a better understanding of people with dementia and their carers amongst our membership.

We will support and lobby for the development of services which enable people with dementia and their carers to feel included, involved and consulted with and that meet individual needs. We promote the delivery of person-centred care, information and support by knowledgeable, skilled staff that is compassionate, promotes dignity, choice and ultimately helps to improve quality of life. The RCN is currently supporting a national project on the care of people with dementia in acute care settings and will be working collaboratively with stakeholders to develop and disseminate this work.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

The specific challenges faced by the nursing workforce in delivering these outcomes include ensuring nurses are able to access good quality training and education. We welcome the focus on improved education and training for nurses and healthcare staff, including NMC guidance on core competencies in dementia and inclusion of dementia in pre-registration curricula. However significant challenges can be faced by staff in accessing appropriate education and in being supported to deliver care which is individualised and appropriate to need. In order to deliver the care that people with dementia and their carers need, nurses need to have ‘time to care’ and be supported by knowledgeable leaders. They also need the freedom to work within systems that support individual choice and promote inclusion. Our Frontline First campaign highlights some of the concerns about the potential changes to services which may pose a threat to the delivery of good care and availability of services. The RCN will act on the information provided by its members to ensure that these changes do not affect direct care.
3. What are your plans as an organisation to respond to these challenges between now and 2014?

- Supporting and delivering a national project/campaign on the care of people with dementia in acute care settings.
- Working collaboratively with other organisations to ensure that good dementia care practice is disseminated and shared.
- Supporting increased understanding of and development of skills in dementia care through sharing of resources to members via forums and online learning.
- Campaigning for specialist nurse roles, including dementia care nurses.
- Supporting the development of nurse leaders, including for dementia care to support and deliver improvements in care.
- Campaigning and raising awareness of the need to protect frontline services, which directly affect people with dementia and their carers.
- Promoting the delivery of dignity in care via an ongoing campaign and sharing of resources.
Skills for Care

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

Skills for Care is uniquely positioned across the adult social care sector to consider workforce and skills development needs. We also have a strong model of joint working with Skills for Health to ensure cross-sector issues are considered and addressed jointly to support people who use services and patients across the two sectors.

Skills for Care, working in partnership with Skills for Health, has developed and is implementing a Workforce Training and Education Development Action Plan to ensure that the sectors have an appropriate qualification framework that supports the National Strategy for Dementia and new government commitment to improving dementia services.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

One of the key challenges Skills for Care is addressing in England is the number of social care workers and employers there are in the sector needing access to dementia-related learning and development opportunities. As part of the Sector Skills Council we work with 1.6 million social care workers, 38,000 ‘traditional employers’ and in the region of 115,000 micro employers all with varying information needs from general awareness to detailed specialist knowledge.

Dementia crosses traditional sector boundaries with individuals passing between health care and social care service provision. Each sector has very different structures, professions, cultures, languages and service funding arrangements. We need to ensure that the workforce is equipped to support individuals moving between health and social care through truly integrated services.
3. What are your plans as an organisation to respond to these challenges between now and 2014?

Skills for Care and Skills for Health have developed a range of units and qualifications (linked to existing National Occupational Standards) which are available on the Qualification and Credit Framework (QCF) from September 2010, these units and qualifications are:

- 8 units at level 2
- 8 units at level 3
- Level 2 Award Awareness of Dementia
- Level 2 Certificate in Dementia Care
- Level 3 Award Awareness of Dementia
- Level 3 Certificate in Dementia Care
- In addition, there are level 2 and 3 dementia specific learning pathways as part of the level 2 and 3 diploma in health and social care (available from January 2011)

Skills for Care has developed, jointly with Skills for Health, and is implementing a Workforce Training and Education Development Action Plan for Dementia.

The Action Plan has been formally submitted under a joint report to the Department of Health. The Plan is being implemented through the range of ongoing Sector Skills Council Commitments for example developing the QCF.

- Skills for Care, jointly with Skills for Health, have developed a range of units on the QCF that support workforce development on dementia specifically.
- Skills for Care is committed to review its range of projects and products to identify opportunities to build dementia specific relevance, as appropriate, into the work streams.

- Skills for Care, jointly with Skills for Health, is developing a range of resources that will support the workforce to support carers better. Version 1 of the framework and supporting resources will be available from Autumn 2010, with Version 2 and impact evaluation findings available from Summer 2011. ([www.skillsforcare.org.uk/developing_skills/workingwithcarers/working_with_carers.aspx](http://www.skillsforcare.org.uk/developing_skills/workingwithcarers/working_with_carers.aspx)).

- Skills for Care jointly with Skills for Health has developed a suite of principles and competences for end of life care. The competences and principles are available on the website ([www.skillsforcare.org.uk/developing_skills/endoflifecare/endoflifecare.aspx](http://www.skillsforcare.org.uk/developing_skills/endoflifecare/endoflifecare.aspx)). Further work to raise awareness, support implementation and to refine and develop these is ongoing and additional guidance and findings will be available from April 2011.

- Skills for Care is committed to ensuring dignity is at the heart of all we do through both our existing products and services and integral to our ongoing work programmes.

- Skills for Care has a range of products and resources that support Strategic Workforce Planning, supported through the Integrated Local Area Workforce Strategies (InLAWs) process.
Old age psychiatrists are mainly responsible in the diagnosis and medical treatment of people with dementia, as well as leading community mental health teams, and providing inpatient services for people with behaviours that challenge. We make sure that highest quality standards are maintained in doing so and support others to deliver better quality care. We also can help to diagnose dementia early and advice on post diagnostic services through accreditation of memory clinics. We are committed to improve standards of care through involvement in general hospitals, through old age hospital liaison services, in care homes, and primary care, not only in terms of assessment and management of people with dementia in these settings, but also in our liaison, training and support role to other professionals working there.

Together with partner organisations eg British Geriatric Society, Royal College of Physicians, Royal College of General Practitioners, Nursing and Midwifery Council, Alzheimer Society/Alzheimer Scotland etc, we will raise awareness of the importance of symptoms of dementia, and advocate for rights of people with the illness. Working with GPs and other commissioners we will encourage early diagnosis and care and referral to specialist services. We will fully involve the person with dementia and their carer in the decision making process. We will become closely involved with governmental committees and seek to improve funding for clinical services and research at national and local levels.
2. What are the challenges to delivering these outcomes from the perspective of your organisation?

We recognise the development of a curriculum for dementia training (our core curriculum for medical training has been accepted by Postgraduate Medical Education and Training Board (now merged with the General Medical Council)). We will ensure that psychiatrists are trained in dealing with all aspects of dementia and train them in team working and team building to ensure the best possible care is delivered. We are committed to involve our consumer group with representatives from voluntary organisations, users and carers in developing this curriculum and examinations. At an individual level it is important to eradicate stigma of dementia and other mental illnesses. It is also equally significant to work with other psychiatrists and physicians to remove stigma of dementia and old age in the medical profession and also to raise their expertise to diagnose and treat dementia. We are aware of bottlenecks in the pathway of treatment of a person with dementia throughout the course of their illness. We highlight the growing elderly population, increase in people with dementia and significant lack of funding to meet their demands for treatment, care and support, compared to general adult psychiatry and other medical specialities.

3. What are your plans as an organisation to respond to these challenges between now and 2014?

- Identify and promote examples of good service delivery across the UK.
- Continue to work on the reduction of age discrimination which is particularly marked in the field of mental health.
- Contribute to the development of a national research agenda incorporating longitudinal studies of ageing, improved recruitment of research participants, and evaluation of secondary prevention strategies for people with current dementia, improved recognition and management of behavioural and psychological symptoms, improved research in care homes and promoting a research culture amongst non-specialist workforce.
- Support and evaluate progress on the English and Scottish dementia strategies and help refine future service developments as a consequence.
- Support our members in delivering the National Dementia Strategy, the NICE Guideline on Dementia and the NICE Quality Standards to improve standards of care.
- Set up formal personal links with other professional organisations to ensure coherence of service planning and the planning of educational and training programmes.
- Work to promote the recommendations of our College report on psychiatric services for black and minority ethnic older people.
- Expand the role of our well established Consumer Forum to ensure more widespread input of the views of people with dementia and carers particularly into training programmes.
- Improve quality standards of memory clinics through national accreditation service and dementia wards through Accreditation for Inpatient Mental Health Services.
1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

- Provision of education and training for professionals.
- Development and dissemination of information resources.
- Campaigning for change.
- Provision of information via national helpline.
- Local support from staff and groups.
- Funding of research.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

- Lack of understanding of Parkinson’s disease dementia as a subtype of the condition, including the underlying aetiology, symptoms and treatment options.
- Sensitivity about acknowledging the level of risk of Parkinson’s disease dementia among people affected by Parkinson’s.
- Lack of integration between movement disorder services and mental health provision.

3. What are your plans as an organisation to respond to these challenges between now and 2014?

- Producing information resources about mental health issues, including dementia, for professionals and people affected by Parkinson’s – mid 2011.
- Undertaking research about how we can better engage with and support people from marginalised groups, including people with Parkinson’s disease dementia – end 2011.
- Influencing the development of national guidelines and indicators for care of people with Parkinson’s, including Parkinson’s disease dementia – 2012.
- Using relevant training opportunities to highlight issues relating to Parkinson’s disease dementia – ongoing.
- Campaigning nationally and locally for high quality services for people affected by Parkinson’s, including those with Parkinson’s disease dementia – ongoing.
- Funding research into predictors of Parkinson’s disease dementia and visual symptoms in Parkinson’s and Parkinson’s disease dementia – underway by 2014.
Skills for Health

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

Skills for Health is the Sector Skills Council (SSC) for the health sector across the UK. Our strategic aim is to develop a skilled, flexible and productive workforce for the whole health sector in all UK nations, to raise the quality of health and healthcare for the public, patients and people who use services.

Skills for Health is uniquely positioned across the whole health sector to support workforce and skills development. We have an effective model of joint working with Skills for Care to ensure cross sector issues are considered and addressed in a way which supports patients and people who use services to move between truly integrated services. This work reflects the different structures, workforce and cultures which exist in each of the sectors.

Skills for Health, working in partnership with Skills for Care, has developed and is implementing a Workforce Training and Education Development Action Plan to ensure that the sectors have an appropriate qualification framework that supports the National Dementia Strategy and the new government commitment to improving dementia services.

We play a crucial role in shaping education supply and provision for the sector but workforce and skills development is wider than just qualifications and we have a range of tools and resources that are relevant to dementia services.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

Diversity of the workforce
One of the key challenges for Skills for Health is the diversity of the workforce and the wide range of differing needs in terms of skills development, ranging from dementia awareness through to detailed specialist knowledge.

Dementia crosses traditional sector boundaries with individuals passing between health care and social care service provision. Each sector has very different structures, professions, cultures, languages and service funding arrangements which can bring challenges for workforce and skills development.

Financial constraints
Against ever increasing financial constraints there is a risk that support and commitment to new or ongoing workforce and skills development will be viewed as a low priority. The challenge is to ensure that employers continue to value their staff resource and recognise the long term benefits to patient outcomes of having a skilled and flexible workforce.

Organisational change
The NHS across England will be undergoing significant structural change over the next two to three years and our challenge will be to support employers during this period to ensure that a workforce which can support effective operational delivery remains a priority.
3. What are your plans as an organisation to respond to these challenges between now and 2014?

Skills for Health Strategic Aims:

• Engage with health sector employers to ensure we can be the authoritative sector voice on skills and workforce development for the whole sector.

• Inform the development and application of workforce policy through research and the provision of robust labour market intelligence.

• Implement solutions which deliver a skilled, flexible and modernised workforce capable of improving productivity, performance and reducing health inequalities.

• Champion an approach to workforce planning and development that is based on the common currency of National Occupational Standards.

Resources specific or relevant to dementia; available or in development:

• Skills for Health has developed National Occupational Standards (NOS) or competences to describe what individuals need to do, what they need to know and which skills they need to carry out to effectively perform an activity. They can be used by all health professions, and all levels of staff, whether in the independent or voluntary sectors or in the NHS.

• Skills for Health has developed and is implementing, jointly with Skills for Care, a Workforce Training and Education Development Action Plan for Dementia.

  – The Action Plan has been formally submitted under a joint report to the Department of Health. The Plan is being implemented through the range of ongoing Sector Skills Council commitments for example developing the Qualifications and Credit Framework. (QCF).

• Skills for Health, jointly with Skills for Care, has developed a range of units and qualifications (linked to existing National Occupational Standards) that specifically support workforce development for dementia services. These will be available on the Qualification and Credit Framework from September 2010, these units and qualifications are:
  – 8 units at level 2.
  – 8 units at level 3.
  – Level 2 Award Awareness of Dementia.
  – Level 2 Certificate in Dementia Care.
  – Level 3 Award Awareness of Dementia.
  – Level 3 Certificate in Dementia Care.
  – In addition, there are level 2 and 3 dementia specific learning pathways as part of the level 2 and 3 diploma in health and social care (available from January 2011).

• Skills for Health is supporting a range of local dementia workforce development initiatives. These will benefit not only the workforce but also people that use services. In some cases, this work may lead to resources that can be made available at a national level for sharing more widely. For example, in Oxford a new role of dementia advisor has been developed working across GP practices, which is now being taken forward to become a National Transferable Role.

• Skills for Health is committed to review its range of projects and products, as appropriate, ensure that the needs of dementia services are reflected.

• Skills for Health, jointly with Skills for Care, is developing a range of resources that will enable the workforce to support carers better.

  – Version 1 of the framework and supporting resources will be available from Autumn 2010, with Version 2 and impact evaluation findings available from Summer 2011.
• Skills for Health, jointly with Skills for Care, has developed a suite of principles and competences for End of Life Care.

  – The competences and principles are available on the website. Further work to raise awareness, support implementation and to refine and develop these is ongoing and additional guidance and findings will be available from April 2011.

• Skills for Health is committed to ensuring dignity is at the heart of all we do, through both our existing products and services, and integral to our ongoing work programmes.

• Skills for Health has a range of products and resources that support Strategic Workforce Planning, including the Six Steps Methodology and a suite of National Occupational Standards.

  – The National Occupational Standards (competences) include a specific suite, which defines the knowledge, understanding and performance criteria for service commissioners and these could support GP consortia as a common building block, for role development, and subsequent education and training initiatives to support these roles. Use of the Six Steps, across any organisation will help ensure that decisions made on workforce design and the recruitment of new staff and teams are sustainable and realistic; and that they fully support the delivery of high quality patient care, productivity and efficiency.

• Internal awareness raising.

  – Ongoing activity to embed consideration of dementia in all skills and workforce development work streams.
Social Care Institute for Excellence

I. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

The Social Care Institute for Excellence (SCIE) is an independent knowledge transfer charity which seeks to drive up the quality of care services by sharing knowledge about what works in all aspects of social care for adults and children throughout the UK. We recognise the central role of people who use services and carers, and we aim to ensure that their experience and expertise is reflected in all aspects of our work.

SCIE does this by working with practitioners, commissioners, providers and those who lead the sector across the UK. It spreads good practice, research findings and practical information in innovative ways. The Dementia Gateway is SCIE’s main offer in the field of dementia. This co-produced, web-based resource has practical information on caring for people with dementia, case studies, Social Care TV films, e-learning programmes on mental health and links to useful resources and other organisations. The Gateway is aimed at those who care for people with dementia in the community and in care homes, relatives and carers.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

About 1.75 million people work in social care. There is a high turnover of staff who are often poorly paid and have a varied level of professional development and qualification. Those caring for people with dementia work in a variety of settings. Some are employed in the private and voluntary sectors while others work for local councils. Reaching staff is therefore a complex process.

SCIE has developed a range of resources which target different audiences in new ways.

Some staff that care for people with dementia do not have easy access to the internet. This makes using the Dementia Gateway, SCIE’s key offer to the dementia care workforce, difficult. The Get Connected project, hosted by SCIE, is helping more care homes and other providers to secure access to broadband.

People with dementia may be at high risk of abuse. It is important to develop cultures, practices and systems which prevent this.
3. What are your plans as an organisation to respond to these challenges between now and 2014?

- Develop and promote the Dementia Gateway to new and existing audiences, including the health care workforce – on-going.
- Produce and promote three new Social Care TV films on dementia and disseminate to key audiences by March 2011.
- To maximise choice and control for people with dementia and their carers, SCIE continues to develop products on personalisation. A new At a Glance briefing on personalisation and mental capacity will examine how people with dementia can be fully involved in decision making. To be launched by November 2010.
- Identify good practice in what local authorities are doing or plan to do to prevent abuse among all groups including people with dementia and disseminate this on the SCIE website by March 2011.
- Develop national commissioning guidance to help local authorities to commission care homes which provide safe abuse-free services for people with dementia by March 2011.
- Produce a research briefing on dementia in black and minority ethnic older people in the UK by December 2010.
- Work with the Department of Health to develop a range of resources on dementia, the first of which is an interactive Early Intervention Toolkit for frontline NHS and social care commissioners to prevent or delay the need for more specialist and life-changing interventions for people with dementia by February 2011.
- A new section of the Dignity In Care Guide will be added on ‘dignity for care workers’, improving the role and status of care workers to underpin service quality by March 2011.
- Support the quality of the Independent Mental Capacity Advocate (IMCA) service. The largest group of people who access IMCAs are people with dementia who, for example, need support in getting care which meet their needs and wishes. Resources to be produced include guides on access to the Court of Protection and the IMCA role in the Deprivation of Liberty Safeguards and six training films by January 2011.
- A project to understand how best to involve older people with high support needs and their carers in SCIE’s work will be complete by summer 2011.
Southern Cross Healthcare

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

We currently have a draft dementia strategy document which is in line with the core outcomes of the draft declaration. This strategic approach will be enhanced by a commitment from Southern Cross Healthcare to undertake a detailed internal review of all dementia service provision to ensure we are well positioned to provide the best care to all service users and to provide a service which is based on evidence and is responsive to the needs of all stakeholders. The current approach focuses on achieving the outcomes through the following: training and development, physical environments that enable, person-centred care that focuses on meaningful activity, supportive relationships and a sense of well-being.

Our role will be to promote residential dementia care that is seen to be responsive to care needs of all and provide a positive choice and a real alternative to living at home people rather than the outcome of a last resort approach.

Southern Cross Healthcare is currently commissioning a high profile external review of service provision to inform future service provision. Once this review is complete Southern Cross Healthcare will appoint a Dementia Lead to manage and orchestrate the delivery of the strategy.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

There is the perception that only dementia specialist services deliver dementia care. Southern Cross Healthcare recognises the need for all staff to recognise that all homes have residents living with dementia. There is a drive to change this perception so that there are core training and environmental standards for all care homes. That is not to suggest that there is no place for specialist services with specially trained staff and environments that are designed with the special needs of people with dementia. However, increasing the level of skills and knowledge and improving environmental standards such as signage and assistive technology will minimise transitions and the effect of transitions.
3. What are your plans as an organisation to respond to these challenges between now and 2014?

National Dementia Declaration Action Plan

The planned review of Dementia service provision at Southern Cross Healthcare will undertake to identify the most appropriate, innovative and timely models of care to ensure the highest standards of care for residents with dementia care needs. Current initiatives include the introduction of:

- Training – Tomorrow Is Another Day Part 1, Southern Cross Diploma Workbook
- Understanding Person Centred Dementia Care, externally sourced and accredited courses at Stirling and Bradford.

Environment

Core standards for signage and decoration are being developed by the estates department. Some homes have used the Stirling Environmental Audit to accredit their physical environments. Many homes have developed their dementia care environments to reflect local interest and involve residents, families and communities in this process.

Person Centred Care

Introduction of the ‘Choices’ and the development of outcome audits. The following are currently less developed and will be developed as part of the longer term strategy:

- Training – Induction awareness training and handbook for all staff. Inclusion of dementia care topics and particularly leadership in dementia care in the Home Manager Training programme. Formalised links with the major training organisations for facilitating placements and providing learning opportunities.

- Assistive technologies – There is only limited use of assistive technologies. These generally take the form of alerts to risk of falls but a more sophisticated approach to technology could ease transitions, protect dignity, provide useful data to assist person centred care and risk assessment and aid communication.

- Person-centred care – Improved care planning documentation, outcome audits that measure well being and staff engagement (DCM, SOFI), a 24-hour, 7-day-a-week approach to activity, involvement of residents and family in selection and recruitment and day to day decision making and local policy making.

Overarching initiatives such as the development of an internal standards framework or benchmarking tool and campaigns to support learning and person centred care such as an Arts in Care programme have not got past the idea stage. Inclusion of this type of idea in a declaration could prove to be a useful impetus. Research has been supported by the Ethics Committee.
Thomas Pocklington Trust

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

Thomas Pocklington Trust provides specialist services for people with sight loss, some of whom may also have dementia, and we commission research and development about sight loss, including concurrent sight loss and dementia.

We will seek to deliver better outcomes for people with dementia and their carers by improving operational practices and by commissioning research and development projects that can inform good practice across housing, care and support.

We are committed to increasing awareness and supporting action to address the needs and aspirations of the growing number of people who have concurrent dementia and sight loss. In 2010 we estimate that at least 100,000 people in the UK have dementia and sight loss and we know that this creates particular challenges for them and their carers and that this dual burden is often the trigger for increased care services, including a move to a care home.

With Alzheimer’s Society and RNIB we actively support the development of the Dementia and Sight Loss Interest Group of VISION2020UK and work to increase mutual understanding and partnership working among practitioners in dementia services and sight loss services.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

Pocklington faces challenges in developing better outcomes for people with dementia and their carers through its operational services and its research and development programme. Across our work we face challenges in raising awareness of the impact of sight loss on people with dementia, and vice versa, and of the value of interventions that maximise vision and support independence, activity and occupation which improve quality of life and make care and support services more effective.

Our operational services for people with sight loss face the challenge of limited resources that temper our ability to deliver specialist services; we need well trained and knowledgeable staff. That requires an adequate training and qualifications system and resources to recognise skills.

Our research and development programme faces the challenge of limited resources to fund the high quality research that is needed to identify and demonstrate positive outcomes from practice and to challenge poor practices.
3. What are your plans as an organisation to respond to these challenges between now and 2014?

- We will work with dementia and sight loss organisations with the aim of increasing mutual awareness and understanding and encouraging collaboration that can result in better outcomes for people with concurrent dementia and sight loss and those who care for them; this is ongoing work and includes an active role in the dementia and sight loss interest group of VISION2020UK.

- Year on year we will seek to secure funds to support and/or commission research and development projects that address the needs and aspirations of people with concurrent dementia and sight loss and those who care for them; this is ongoing.

- We will work with other organisations that are seeking to undertake research and development projects around dementia and sight loss so that our research findings and experiences in practice may inform their work and that findings from other research informs our research and practice; this is ongoing.

- We will seek to ensure that staff in our operational services understand dementia and its effects and, as appropriate and possible, we will draw on specialist resources to ensure that; this is ongoing.
WRVS

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

WRVS is a national charity committed to ‘making Britain a great place to grow old’. With over 45,000 volunteers throughout Britain we already support older people to live the lives they want — through practical local support that helps them stay independent at home and active in their local community.

From our recent Social Impact Assessment we know that 89 per cent of the older people we support feel less isolated after using WRVS services. Through understanding what each individual older person needs, WRVS services can support and re-connect people in ways appropriate to them. Whether through one to one activity, through befriending services, or in a group setting such as a social club, local WRVS services stimulate the social interaction so important to people with dementia.

In particular the capturing of oral history, such as through the WRVS Heritage Plus project and subsequent sharing of best practice across Britain, enables older people and particularly those with dementia to stimulate and share their memories.

Finally WRVS believes by investing in preventative services we will transform the lives of people with dementia and their carers. It is through the provision of practical local services such as community transport, enabling older people to get to where they want to go, and home from hospital services, giving confidence when they return home after a stay in hospital, that WRVS helps people to stay in their own homes and be active in their local community for as long as possible.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

WRVS needs three things to help us help older people with dementia. As one of the largest volunteering charities in the country, we rely on the time and energy of our dedicated volunteers to make a difference to the lives of older people. It is a challenge to find ways of attracting new groups of volunteers — including younger people wanting work experience to get a good career, those on a career break and those who find themselves with time on their hands. These are not the traditional type of volunteer and for them, supporting people with dementia may need greater training, or particular people skills. We need to inspire young people to know that everyone, everyday, can make a difference to the lives of other people.

Secondly we need referrals. We need older people to know that we can support them. People come to us in a wide range of ways — through their doctors, their friends and family or on the recommendation of their neighbours. As a charity, we focus our activity on service provision rather than promotion but it is a real challenge to enable people to be aware that we can help them.

Finally our services need funding. With the tight budget environment, it will be a challenge to ensure that ‘that little bit of help’ is not lost in the move to ring-fence those with higher care needs.
3. What are your plans as an organisation to respond to these challenges between now and 2014?

WRVS plans to reach out to existing and potential partners to share the proven impact of the services we provide and stimulate both potential referrals of older people – including those with dementia – and funding, to enable us to help more people. Our growth strategy is ambitious and will enable us to share best practice from one community to another.

We are already attracting new types of volunteers by developing new opportunities, streamlining our own process, and increasing our visibility nationally. We have also developed new partnerships to support us as a national organisation that responds locally.

Most of all we are focussing on being clear about the social impact of what we do, of the difference we make to older people’s ability to live well. We are joining up all our services, integrating the service that people receive in their homes, in hospitals and in the community and putting older people in the driving seat of outcomes-based services that are tailored and relevant to each individual.
Stroke Association

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

We believe there is an urgent need for better recognition of vascular dementia and better information about vascular dementia following a stroke to be available to stroke health professionals, those affected by stroke and those who work in care settings.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

Vascular dementia is often missed in people who have had a stroke because there is little awareness of the condition and a firm diagnosis cannot be made for up to three months after a transient ischaemic attack (TIA) or stroke.

An estimated two thirds of vascular dementia is caused by strokes or TIAs. Despite this link there is no mention of vascular dementia in the Stroke Strategy.

We need to get vascular dementia on the agenda of stroke health professionals.

3. What are your plans as an organisation to respond to these challenges between now and 2014?

We will seek to increase awareness and understanding of dementia and stroke amongst stroke professionals, stroke survivors and their families so that the signs are recognised earlier and people are referred to a dementia specialist.

We will provide relevant information, advice and support to stroke survivors with dementia.

We will seek to ensure that the review process is able to identify those stroke survivors with dementia and make referrals.
Appendix

Template for action plans sent to organisations
National Dementia Declaration Action Plan

Template for organisations to set out what they are doing to support delivery of the National Dementia Declaration

This template is for organisations supporting the National Dementia Declaration to set out what they intend to do by 2014 to transform quality of life for people with dementia. Supporting statements from organisations will be published with the Declaration in October in a booklet and online.

1. The National Dementia Declaration lists a number of outcomes that we are seeking to achieve for people with dementia and their carers. How would you describe your organisation’s role in delivering better outcomes for people with dementia and their carers?

The intention of this question is to allow you to describe your role in delivering the outcomes described for people with dementia and their carers. Your response could include a national and local role. Consider the role you have in influencing and supporting the work of other organisations as well as the projects you deliver. (Word limit of 200 words).

Please write your answer to question 1 here.

2. What are the challenges to delivering these outcomes from the perspective of your organisation?

This question is to allow you to set out some of the key challenges to delivering for people with dementia from your organisation’s perspective. For example, a Royal College might state the challenge on its members understanding about dementia. A training body might say that there is no agreement on what a core curricula should be. (Word limit of 150 words).

Please write your answer to question 2 here.

3. What are your plans as an organisation to respond to these challenges between now and 2014?

This question seeks to understand what specifically your organisation will do to support delivery of the outcomes for people with dementia given the role that you have identified for your organisation and the challenges you have set out. You could describe activities that are already happening or those being planned. Additionally you might want to consider whether there are other opportunities to incorporate dementia into your general work. For example, are there programmes of work you are currently progressing that could benefit people with dementia and their carers. Where could you commit to dementia being supported within that work?

The scope of activity you describe could be anything you are doing that relates to people with dementia along the dementia care pathway, from awareness of dementia, through diagnosis to the end of life. It could relate to outcomes for people in any setting – in the community, in hospitals, and in care homes. It could include description of national and local activities your organisation will be delivering.

For the purposes of formatting the eventual list of organisations’ commitments to publish in October can we suggest that you put together a bulleted list which is no longer than an A4 page that contains no more than 10 bullet points. The more specific the list can be with milestones the more useful it will be.

We appreciate that for some organisations specifying work out as far as 2014 might not be possible.

Please write your answer to question 3 here.