

Delivering the National Dementia Declaration for England

First Quarterly Progress Report February 2012

A list of organisations that we have received a First Quarterly Progress Report 2012 from are as follows:

1. Age Related Diseases and Health Trust
2. Age UK
3. Alzheimer's Research UK
4. Anchor
5. Age Related Diseases and Health Trust (ART)
6. Bradford Dementia Group
7. British Association of Occupational Therapists and College of Occupational Therapists
8. British Geriatrics Society
9. Bupa
10. Care UK
11. Dementia Advocacy Network
12. Dementia Services Development Centre
13. Dementia Life
14. Department of Health
15. Four Seasons Healthcare
16. Hft
17. Housing 21
18. Housing and Dementia Research Consortium
19. Innovations in Dementia
20. Joseph Rowntree Foundation
21. Life Story Network
22. Lloyds Pharmacy
23. Lost Chord
24. Mental Health Foundation
25. MHA
26. National Care Forum
27. National Council for Palliative Care and Dying Matters Coalition
28. National Development Team for Inclusion (NDTi)
29. National Institute for Health and Clinical Excellence
30. NHS Alliance
31. NHS Confederation
32. NHS Institute for Innovation and Improvement
33. Parkinson's UK
34. Pictures to Share C.I.C.
35. Priory Group
36. Royal College of General Practitioners
37. Royal College of Nursing
38. Royal College of Psychiatrists
39. Skills Academy
40. Skills for Care
41. Social Care Institute for Excellence
42. St. John Care Trust
43. WRVS

The remaining members had nothing further to report this quarter.

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Introduction

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.

There are 570 000 people living with dementia in England now, by 2025 there are expected to be 900,000. Dementia is an incurable condition caused by diseases of the brain that over time seriously impair a person's ability to live independently. The majority of care for people with dementia is provided by family members, who are often subject to considerable emotional, physical and financial stress.

The 48 national organisations signed up to the National Dementia Declaration have formed the Dementia Action Alliance. This has now grown to 77 including a number from across the regions. The Alliance calls on all families, communities and organisations to work with them to transform the quality of life for the millions of people affected by dementia.

All organisations included in the Dementia Action Alliance have completed a template detailing their plans for delivering the outcomes from the National Dementia Declaration for England between 2010 and 2014. These plans can now be viewed on the Dementia Action Alliance website. **In January and February 2012 members of the Alliance submitted their first quarterly progress reports on their plans, which are set out in this document.** Specifically members were asked to update on their plans as an organisation to respond to the challenges to delivering better outcomes for people with dementia and their carers between September 2011 and February 2012. This document also includes the first quarterly progress report of those members of the Dementia Action Alliance who submitted them in February 2011.

360 Forward

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

- Having identified the problem of engaging the views of those with dementia, we are working with a Stirling University project to develop a customised tool to enable those with dementia to express their views and care experience within the 360 Standard Framework Audit.
- On completion of the above project we plan to train our practitioners to incorporate this development in future audits relating to those with dementia
- By raising the profile of the 360 Standard Framework as a standard kitemark for quality of care, including for those with dementia for a relationship centred culture, underpinning all service and practice standards. This will enhance the delivery of desired quality outcomes to those with dementia, their families and carers by incorporating their voice when measuring outcomes and developing actions for improvement.
- 360 Forward is seeking to influence the training of nurses to meet the needs of the specific needs of the elderly and those with dementia
- 360 Forward is seeking to collaborate in providing a training and qualification route for careers incorporating the needs of the elderly and those with dementia.

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360 Forward are a new member and therefore have nothing to report this quarter.

Age Related Diseases and Health Trust (ART)

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

- Our primary objective, from which all the following points flow, is to increase our effectiveness as a catalyst within and between sectors. By facilitating cooperation we find we can help stakeholders overcome obstacles and make new connections.
- We'll be increasing our fundraising capability for R&D, including vitamin D, fat derived hormones such as leptin, and adiponectin and zinc-alpha2-glycoprotein. Also fundraising for direct services to sufferers and carers as in the next item, and for fast and free online 'best practice' info for practitioners from the Cochrane Collaboration. These objectives include direct fundraising and facilitating joint endeavours between researchers, and between researchers, charities, sponsors and major donors.
- We are determined to increasingly support the national rollout of services provided by the Guideposts Trust. These include dementia information lines for sufferers and carers, the popular all-age dementia information resource <http://www.dementiaweb.org.uk/>, training and consultancy for care homes, training sessions for family carers (working in partnership with local Alzheimer's Society and Carers Centre Colleagues), and music therapy delivered by qualified music therapists. The aspiration to develop a free dementia home nursing service is also one we will seek to pursue.
- Building on early positive feedback from Government, we will be working towards initiatives assisting older people to have second and third careers helping other older people. One key aspect of this will be Advocacy in the health service - safeguarding and promoting the welfare of sufferers and carers in hospitals and care facilities. We will seek to make this part of improving the patient's (and carers) journey for all-cause dementias.
- We hope to facilitate the early creation of an action group within the DAA to make early diagnosis, and improved pathways to the best possible treatments and care support, a national priority. We will seek to introduce funding for this purpose, allowing and encouraging relevant DAA members to act affordably and effectively together. 2014 is a reasonable and necessary time frame to achieve truly high level pathways nationwide in this regard.
- The true extent of the "demographic time bomb" of dementias is not sufficiently clear to either the public or decision makers. Dealing with this effectively is possible and affordable. Not doing so guarantees a human and financial disaster. We will seek to aid all interested parties in making this unavoidably clear. To this end we are looking at developing films and TV programmes and bringing in relevant sponsorship. We will consult with the Alzheimer's Society and DAA members to see if films, additional PR capabilities and event

sponsorship can combine in adding strength to the 2012 national conference.

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The National Dementia Declaration calls for people with dementia and their family/carers to receive an early diagnosis which was sensitively communicated.

The Age Related Diseases and Health Trust (ART) has been working to further this outcome since 1 November 2011 by conducting interviews and running workshops and debates to explore:

- who is taking action to promote the diagnosis of dementia
- what obstacles are perceived to be preventing improvements in this field
- where practical interventions could make a difference

This work will form the basis of a report to the Dementia Action Alliance in early March 2012 and will feed into the February quarterly meeting of the DAA and into the All-Party Parliamentary Group inquiry which is expected to report in June 2012.

ART is also leading the DAA's workstream on early diagnosis, and hopes to attract funding to enable it to co-ordinate campaigning activity in the remainder of 2012 to further some of the practical interventions recommended in the report detailed above.

Age UK

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

- 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.

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Specific areas to highlight for this quarter are:

Research

- In 2011 we continued to fund existing research projects on dementia and age-related cognitive impairment, through our Research into Ageing programme. We continued to fund 5 projects on dementia at a total value of £430,000. We continued to fund 3 projects on age-related cognitive impairment at a total value of £387,000.
- In addition, we continued to fund Phase 2 of The Disconnected Mind, a major project on cognitive ageing at the University of Edinburgh,

committing £500,000 for the first year (of five) of Phase 2 of the project (2011 to 2016).

Shaping our services

- As part of our action plan we committed to consider practical ways in which our services could be adapted to ensure they meet the needs of people living with dementia and their carers.
- Our Information and Advice team is responding to our commitment by evaluating the current range of Age UK Guides for older people when due for their regular review. The aim is to identify occasions when information or an “action” would be of particular relevance to an older person living with dementia or their carer. As an example, in a forthcoming revision of our Guide – Caring for your eyes – there will be reference to the importance of regular eye tests for people with cognitive or communication difficulties such as dementia.
- With the help of carers of people living with dementia who use Age UK services, we are planning to produce a Guide for carers of people living with dementia. Visits to a range of local services, followed by a postal survey of carers have helped us confirm the range of topics to be included in the Guide. A number of carers confirmed their interest in reviewing draft copy and helping with the Guide design. It is hoped to have the Guide available by middle of 2012.
- We have initiated a new programme of work to look at key service areas for Age UK nationally and locally. We will ensure that the needs of people with dementia and carers are considered as an integral part of these services. Specifically we have committed some resources to support service design and innovation and we will ensure that at least one of the projects supported through these resources will focus service design for people with dementia and/or carers.
- We have received some new restricted funding to support work on falls prevention, based on existing evidence of the physical exercise needed for effectiveness. We will be working with three of our local partners over the next three years to test out how best to deliver and support this exercise in a range of settings. At least one of our partners will be testing out how this can be organised and supported in a community-based setting for people living with dementia.

All-Party Parliamentary Group on Dementia

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.

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In December, the APPG on Dementia launched an inquiry into early diagnosis. Currently only 43 per cent of people in the UK living with dementia ever receive a formal diagnosis, therefore this inquiry will bring together more evidence and understanding about the current problems there are to improving diagnosis of dementia. Evidence was submitted by people with dementia, GPs, carers and a wide range of other respondents on their experiences and views on getting a diagnosis. Oral evidence sessions will take place in parliament in March, where people involved with or affected by dementia will share their experiences on diagnosis with MPs and Peers.

The APPG on Dementia has also met with the Minister for Care Services Paul Burstow in early February 2012 to discuss the future of the care and support system, an issue crucial to the well-being of people with dementia.

Alzheimer's Research UK

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 unravelling 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.

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On 25 January 2012, Alzheimer's Research UK launched its report *Defeating Dementia*.

- This takes a detailed look at research capacity in the UK dementia field – capacity not only refers to the number of researchers working in the field, but also our ability to take new scientific discoveries forward and capitalise on our research strengths. The report shows that despite the fact that dementia costs the UK economy more than cancer and heart disease combined, for every researcher working on cancer, there are around 6 working on dementia. However, despite low capacity, the quality of UK dementia research is world class and the UK is a global leader in the field.
- The second half of the report draws on feedback from 120 research scientists working on dementia, with their views on how the UK can improve its research capacity to help the field achieve even more. Based on this evidence, the report makes 14 recommendations for Government and relevant research funders. Above all, it calls for a National Dementia Research Strategy with long-term, protected funding. It also looks at other

barriers to progress, including limited research career pathways and regulatory issues.

At a very well-attended launch at the House of Commons, the report was warmly welcomed by Professor Alistair Burns, the National Clinical Director for Dementia Research. The large number of attendees included Parliamentarians, industry and other research funders, as well as a significant number of research scientists and people with experience of dementia from different parts of the UK.

The report can be downloaded from our website:

[http://www.alzheimersresearchuk.org/siteFiles/resources/documents/reports/A_RUK_Defeating_Dementia -
_Building capacity to capitalise on the UKs research strengths.pdf](http://www.alzheimersresearchuk.org/siteFiles/resources/documents/reports/A_RUK_Defeating_Dementia_-_Building_capacity_to_capitalise_on_the_UKs_research_strengths.pdf)

Alzheimer's Society

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 help lines.
- 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.

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Alzheimer's Society has nothing to report for the past quarter

Anchor

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

- 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 session and one to one support as needed.
- We positively encourage people with dementia to influence the services we provide with residents forums across the different settings in which they live. 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 coordinator to support individual's interests.
- Supporting skills and knowledge of individual roles such as activity coordinators in our care homes
- Review the use of antipsychotic medication in our care homes.

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Since reporting progress in the annual report November 2011:

We have continued to invest in our employee's development to support and care for Anchor customers with the delivery of specialist dementia training and support by our dedicated Dementia Specialist team.

- In the last 3 months in line with our training calendar of induction and development:
 - 152 employees have completed the dementia awareness session Introduction to Dementia Care.
 - 96 employees have attended and completed the intermediate session, Improving Dementia Care.
 - 351 employees attended Mental Capacity Act 2005 awareness training.
 - Colleagues continue to undertake MUST Malnutrition Universal Screening Tool training session to ensure additional knowledge and understanding of importance of good nutritional care.
 - 280 employees attended a wide range of dementia knowledge development sessions, many are bespoke to meet individual service need including, customers life stories, understanding communication as behaviour, night time activity, depression, later stages of dementia, enhanced dining, positive risk assessment, and understanding a supportive environment.

We continue with the rolling programme for families and friends for our existing and new customers of information and education sessions.

- Since last report we have held 7 sessions around the country 32 people attended, many requiring additional advice.
- Dementia Specialist key contacts supporting individual family and friends across the country to help gain understanding of dementia and the impact of the illness on the person, how to develop customers living stories and adapting to changing communication needs and different behaviours.
- Signposting family and friends to local specialist support services for additional support and advice.
- Continuing to build community links by meeting with other organisations such as Age UK, NAPPA, WHELD project and Home Instead Senior Care to share ideas and initiatives.
- Continuing with community art project encouraging and supporting customer's involvement from all services in the organisation.

The volunteer initiative continues to make significant progress.

- We currently have 88 volunteers on site all matched with individual customers to meet specific individual interests. A further 76 offers of a volunteering placement are waiting for a CRB disclosure and references, these come from a wide range of backgrounds such as health and social care students, medical and dental students, unemployed people looking for a career change and wanting to gain work experience.
- We have 39 volunteers who have completed their 6 month volunteering commitment. In addition 6 of these people have now applied for a permanent care post and have been successfully recruited.
- Recruitment of volunteers continues and on average we are interviewing 8 potential volunteers per week.

Continuing to support individual and groups of employees such as activity coordinators and dignity champions in leading the development of customers living stories.

Having promoted customer life stories over the last 12 months in care homes we have doubled the number that have commenced, this positive trend has continued over the last 3 months.

- Closely working with activity coordinators and team leaders to improve knowledge and understanding of the individual living with dementia to create more individual based activity to focus on everyday living.
- Focus on planning special events for forth coming Dignity in Action day.
- Supporting activity coordinators to develop bespoke packs of communication cards from large generic set for individual customers to enhance living experience.
- Planning and developing sensory gardens to encourage customers to use outside space.

Continuing with our on-going review of the use of antipsychotic medication for customers in our care homes. Following the initial reduction of 2% to approximately 9% of customers with dementia receiving antipsychotic medication the trend for reduction continues.

- Understanding antipsychotic medication training sessions have been delivered to many managers and team leaders to provide additional support to understand the use and misuse off antipsychotic medication.
- We are using specific documentation to ensure if a customer is prescribed antipsychotic medication this is monitored and reviewed regularly.
- We are continuing to support customers and colleagues through the review of and withdrawal and building strong links with GP's and CPN's the number of reveiws has increased, Focusing on each region we have evidence of increased active reviews, for example in Surrey from 62% to 78%.

Association of Dementia Studies, University of Worcester

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

- 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.

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The Association of Dementia Studies, University of Worcester has nothing to report for the past quarter

Association of Directors of Adult Social Services

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

- 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.

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The Association of Directors of Adult Social Services has nothing to report for the past quarter

Bradford Dementia Group

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

- 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.
- 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.
- 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.
- 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.
- We will further develop of 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.
- Bespoke consultancy service will be further developed to assist organisations and individuals to transfer research into practice in a timely and appropriate manner.
- 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.
- 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.
- 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.
- We will support our key academics to work alongside people with dementia and their families to influence national and international policy in dementia care.

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Education:

- We are evaluating the usefulness of a short film, *Bay Tree Voices*, from the perspectives of students and service user and carer representatives. We made the film with people with dementia who attend a local day centre.

Research:

- With funding from National Institute of Health Research School for Social Care Research, we are involving people with dementia in creating photographic images of their perspective of the home care environment.
- With Programme Development Grant funding from the National Institute of Health Research to improve health care in care homes, we have been working with our carer reference panel to get advice on recruitment and data collection.
- With funding from the School of Health Studies, we conducted a literature review on participatory action research (PAR) with people with dementia and their families. We will present a poster of this work at the Alzheimer's Disease International 2012 conference in London.
- We have been using participatory video to facilitate the involvement of people with dementia. We presented this work at the 2nd International Visual Methods conference.

Practice Development/Consultancy

- We have engaged people with dementia and their carers to help shape our practice development work.

In collaboration with colleagues at Barnsley Hospitals NHS Foundation Trust and Bradford Teaching Hospitals NHS Foundation Trust we have designed and will deliver and evaluate a training intervention to provide sustainable improvements in the acute care for people with dementia.

We continue to work with Cannon Care Homes to develop and maintain a model of excellence in their care homes. We are currently involving all staff in identifying ways they can support residents' sense of control and self worth.

We continue to work in partnership with Bupa Care Services. We have delivered *Celebrating success development days* for Person First Coaches who we trained 9-12 months ago. We will be running a series of these days over the coming months in addition to continuing to train additional Person First Coaches.

We are working with Opera North to develop and evaluate a drama group which engages with people with dementia and their carers from the local community.

- We have held our first staff drop-in information and support group for University of Bradford employees who are family carers to people with dementia.

- We have been commissioned by the Joseph Rowntree Foundation to write a review paper about how society can and should adjust to dementia.
- One of our PhD students presented her work on stigma and primary care at the 2011 Alzheimer Europe conference in Warsaw and to colleagues at the University of Nijmegen. Her further work in this area will be presented at the Alzheimer's Disease International 2012 conference in London.
- Our training, education and practice development consultancy continue to actively challenge the stigma of dementia, both at organisational and individual levels

We are in the early stages of a National Institute of Health Research collaborative project exploring ways to improve healthcare in care homes and to reduce avoidable hospital admissions.

We have been awarded funding from the National Institute of Health Research School for Social Care Research to carry out an 18 month participatory video project with people with dementia in long-term social care.

Training:

We have launched two new courses:

- Leadership in Person- Centred Care
- Dementia Care Mapping in Supported Living (DCM-SL)
- We continue to consult and work with organisations to develop bespoke training packages, tailored to meet their individual needs.

We continue to deliver a programme of training throughout the UK including:

- Activities and Occupation in Dementia Care
- Cornerstones of Person-centred Dementia Care
- Dementia Awareness
- Dementia Care Mapping
- Dementia Champions
- End of Life Care
- Legal Issues in Dementia
- Person-centred Dementia Care

Our international strategic partners continue to deliver our training course in Dementia Care Mapping in the following countries: Belgium, China, Denmark, Germany, Italy, Japan, the Netherlands, Norway, Singapore, Spain and Switzerland.

We have been invited to serve on the steering group for the Focussed Intervention for Training Staff project.

We have been training Care Quality Commission staff in use of the Short Observational Framework for Inspection.

Accredited Education– BSc and MSc dementia studies:

- Our service-user and carer sub-committee of the Course Management Team (CMT) for our undergraduate and post-graduate degree programmes has now met and elected a member to the full CMT.
- We engage in continuous quality improvement to ensure all the learning activities reflect cutting edge practice in relation to teaching and learning, and make use of the best available resources including video and other materials.

We are currently engaged in a number of consultancy projects in a range of settings including: acute care, older people's mental health, care homes and supportive living.

We are developing a web portal to enhance our customers' experience of our consultancy services.

We have conducted Dementia Care Mapping evaluations for Derbyshire County Council as part of a larger project around the reduction of antipsychotic medication for people with dementia.

Our evidence-based consultancy service is being further developed using a range of methodologies including Dementia Care Mapping, balanced scorecards, focus groups and interviews.

Research Bids:

- We continue to hold monthly dementia research bid development meetings with colleagues across the University and local NHS trusts.

Dissemination:

- We are using Facebook and Twitter as an additional means to share progress and disseminate findings of our research.
- We will shortly be uploading video clips to our web site of our academics talking about their research.
- Our research findings continue to be integrated into our evidence-based training, education and practice development work.

We are reviewing pricing for our accredited distance learning courses in light of the government's reduction in HEFCE funding.

- We are developing a schedule of public lectures about contemporary issues in dementia care to be held at the University of Bradford.
- We are working with colleagues across the University, to support and promote the University of Bradford as a dementia-friendly institution.
- We gave a presentation on the use of Dementia Care Mapping to facilitate organisational change and promote Human Rights to health and social care practitioners at the Practitioners Alliance Against Abuse of Vulnerable Adults in Kent.
- We participated in the debate at the November 2011 Dementia Action Alliance meeting arguing in favour of the motion that 'the most important route to boosting early diagnosis is improving GP understanding rather than increasing public awareness'.

- We have critiqued an article on experiential learning in *The Independent* 'Dementia: a small taste of hell on earth'. It available on-line and there is a link on our Facebook page.

Our National Institute of Health Research Programme Development Grant exploring ways to improve healthcare in care homes represents a collaboration between academics, family carers and care providers. This study is designed to produce findings which will be relevant for national and international policy.

We have contributed to the forthcoming The World Health Organisation report on dementia – public understandings of dementia.

We serve as an Alzheimer Europe Expert Advisor on Social Care, on the International Advisory Board for the Alzheimer's Disease International Meeting in March 2012 and are members of the European Research network on interventions for early dementia (INTERDEM)

Within the UK we serve on the following advisory groups:

- Alzheimer's Society (UK) Research Advisory Council Executive
- Department of Health National Dementia Strategy Workforce Development Committee
- Joseph Rowntree Foundation A Better Life for People with High Support Needs Programme Advisory Group
- National Institute of Health Research Clinical Studies Group for the Dementia and Neurodegenerative Diseases Research Network (DeNDRoN)
- National Institute of Health Research Enabling Research in Care Homes Project Board (ENRICH)
- National Dementia Strategy Implementation Reference Group (2009-present)

British Association of Occupational Therapists and College of Occupational Therapists

Please note that here we set out the organisation's plans to deliver better outcomes for people with dementia and their carers between October 2010 and 2014, and below each bullet point what progress has been made in the first quarter (October 2010 to February 2011)

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

COT will be supporting the Dementia Declaration through a number of key actions.

- 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.

Progress: First drafts expected to be completed by April

- 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 the College of Occupational Therapists website with resources and ideas for implementing the guidance for older people, including people with dementia.

Progress: Activity Matters Toolkit is on the College of Occupational Therapists Website

- Review existing or produce new resources to advise carer's on different aspects of daily care with partners from other organisations. For example: In collaboration with the Chartered Society of Physiotherapy, the College of Occupational Therapists 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.

Progress: Currently liaising with the Chartered Society of Physiotherapy regarding a resource for carers on seating and posture.

- Promote an understanding of the nature of occupation and its importance to health and wellbeing 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.

Progress: Leaflet designed jointly with the Dementia Services Development Centre

- Involvement in the Memory Services National Accreditation Programme through Membership of the Standards Development Group and Accreditation Committee.

Progress: Ongoing

- Producing a resource document on commissioning and planning occupational therapy services for people with dementia

Progress: Planned for summer 2011

- Develop resources for occupational therapy staff to implement recommendations within the End of Life Care Strategy for people with dementia. Action: Produce an electronic document by 2012.
- 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).

Progress: Initial meeting on 23.02.11

- Exhibiting at conferences (for example: the DSDC Coming of Age: Dementia in the 21st Century conference) and facilitating seminars

*Progress: Exhibited at NHS Alliance
Co-chaired session at the British Geriatric Society
Seminar at the Care Homes Exhibition (Birmingham) on the
Need to be active does not diminish with age*

First Quarterly Progress report 2012

Please note that here we set out the organisation's plans to deliver better outcomes for people with dementia and their carers between October 2010 and 2014, and below each bullet point what progress has been made in this quarter (Jan. 2012)

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

COT will be supporting the Dementia Declaration through a number of key Actions:

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.
- *Progress: Dementia topic section on COT website with a range of resources is now active.*
- Action: Providing training to occupational therapists working in general hospitals to increase their knowledge of dementia- focusing on gaining knowledge of who the person is, communication, enhancing the environment, offering opportunities to be active and enabling risk.
- *Progress: 3 study days completed and a network event run for occupational therapists in liaison psychiatry.*

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 the College of Occupational Therapists website with resources and ideas for implementing the guidance for older people, including people with dementia.
- *Progress: eLearning tool in development to support the Activity Matters Toolkit.*

Review existing or produce new resources to advise carer's on different aspects of daily care with partners from other organisations.

- For example: In collaboration with the Chartered Society of Physiotherapy, the College of Occupational Therapists 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.

Progress: No change

Promote an understanding of the nature of occupation and its importance to health and wellbeing and the contribution that occupational therapists make to services for people living with dementia.

- *Progress: Informing expert groups, responding to consultations- ongoing.*

Explore joint working with National Association for Providers of Activity (NAPA).

- *Progress: Reference group and plan of work agreed to revise Activity Provision. Benchmarking: good practice in care homes.*

British Geriatrics Society

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

Progress: Achieved to fair degree

- Consultee to NICE on the Drugs for Dementia Guideline 2010

Progress: Fully Achieved

- Document on Pain assessment in the older patient (BGS, BPS, RCP) –

Progress: Useful to consider promotion again this year

- Document on Pain management in older people should include dementia

Progress: In progress

- BGS statement on mental capacity 2010

Progress: Achieved

- Regional study days to facilitate local hospital leads for dementia

First Quarterly Progress report 2012

The British Geriatrics Society's Cerebral Ageing and Mental Health Special Interest Group is drafting guidance relating to the recommendations of the National Dementia Audit which encouraged Royal Colleges to provide expert advice on: brief screening tools for cognitive function and delirium for the assessment of people with dementia and older people in the general hospital; tools for the standardised assessment of functional ability and for the assessment of pain in people with dementia and circumstances in which prescription of antipsychotics is appropriate. The BGS is also providing evidence, in conjunction with the Royal College of Physicians, to the APPG on Dementia's Inquiry into how to improve dementia diagnosis rates across the UK.

The BGS Spring Meeting is taking place from 16-18 May in Llandudno, North Wales. There will be a special focus on 16 May on the latest developments in

the field of neurodegenerative disorders, including presentations on the practical and future management of dementia in Parkinson's and Lewy body disease; psychosocial intervention in dementia and alternatives to neuroleptics in dementia. If you are interested in attending please see the BGS website: www.bgs.org.uk

The BGS Dementia Lead Louise Allan is working with the BGS England Council to develop training for dementia champions which would be delivered at BGS regional meetings.

The BGS is supporting the Mental Health Forum, a one day conference taking place in London on 23 May..

Bupa

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 e.g. 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 continuity of care by involving the family, local community and primary care and by maintaining the same care setting until the end of life.
- Ensure that each resident has a respectful and dignified death in line with the principles of Person First and that families are re-assured 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.

First Quarterly Progress report 2012

Our social media work continues with video blogs posted on our Facebook page and You Tube. In November in partnership with Alzheimer's Australia Bupa launched BrainyApp, a dementia-awareness, risk-reduction mobile app.

Courses being held to replace leavers and provide a Dementia Champion to every new or newly registered dementia specialist unit. Currently 204 had been trained (as of 31st December 2011)

More than 11,170 people have now completed or are underway with The Essentials foundation training. 152 Person First Coaches have been trained (as of December 2011) to deliver the Excellence core modules of more advanced or specialist care skills and knowledge.

In November smart analysis of care homes with high-prescribing rates of antipsychotics revealed a significant proportion of residents are prescribed antipsychotics before arriving to live in a care home. There are significant regional variations but in some areas of the UK over 70% of residents taking antipsychotics were prescribed these medicines before admission. Action continues to be taken to reduce prescribing of antipsychotics. This information is being shared within the DAA/NHS Institute for Innovation and Improvement 'Leaders of Care Homes' commitment group

At the UK Dementia Congress in November Bupa presented with our partners at Bradford University's Dementia Research Group the outcomes of our Person First training programme that advances best-practice in person-centred dementia care.

Collaboration with the Helen Hamlyn Centre, Royal College of Art resulted in the development of an interactive website- **bettercarehomes.org** – a tool to disseminate design guidance that helps designers appreciate the range of disability accommodated in care homes in order to support social inclusion, enhance life quality and compensate for disability.

At the UK Dementia Congress the inaugural Bupa Award for Innovation in Person Centred Care which recognises a University of Bradford Dementia Studies' student who has demonstrated exceptional innovation and creativity in translating their learning into practice, in order to benefit people with dementia, their families or colleagues was awarded.

Care Quality Commission

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 which are of particular importance in defining what good quality care for people with dementia will look like, such as:
 - 1 - Care and welfare of people who use services (Regulation 9) - in our standards document we promote a person centred approach to care and treatment
 - 2 - 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
 - 3 - 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
 - 4 - Meeting nutritional needs (Regulation 14) - including encouraging and supporting people to receive adequate nutrition and hydration
 - 5 - 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
 - 6 - 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.
 - 7 - 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 for further details of these and our other proposals.

First Quarterly Progress Report 2012

The Care Quality Commission has nothing to report for the past quarter

Care UK

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.

First Quarterly Progress report 2012

Care UK's programme of innovative dementia care and consistently high investment in outstanding new homes continues to move on apace, with the appointment of our first-ever Head of Dementia Care and with building work beginning on five new sites for specialist homes.

Maizie Mears-Owens has been appointed as Head of Dementia Care to ensure that excellent levels of care are experienced in Care UK's 89 homes and day centres. Maizie, along with Karen Morrison, who has just been appointed as Regional Director in the north, developed Care UK's dementia policy and she will be responsible for its roll-out nationwide.

Maizie is currently recruiting specialist dementia trainers who will not only train all staff employed by Residential Care Services, but will also help home and service managers to review their properties; they will then be able to see how the environment affects residents with dementia and how changes to layout and décor could enhance their wellbeing.

They, along with other trainers, managers and regional directors, will be working closely with former Southern Cross homes to ensure our ethos is understood and in action. They will also share some of the innovative ideas created in those homes, such as baking clubs and reminiscence rooms.

Care UK is developing new homes in Edinburgh, Orpington, Hailsham, East Grinstead and Halstead, all being built as part of its commitment to 30 new specialist homes in the next five years. Our research and experience in how good, well thought-out environments affect the health and activity levels of people with dementia is being put to excellent use in the homes' designs.

In Edinburgh, the home has been designed by Richard Pollock, of Edinburgh-based practice Burnett Pollock Associates, who is also the Dementia Services Development Centre's Director of Architecture at the University of Stirling.

Richard is an international expert in creating buildings that help people with dementia to lead calm, happy and fulfilled lives.

We are also working with his wife Annie, a landscape architect who creates gardens designed for people with dementia, to create a home and grounds that are beautiful, functional and homely. Heather View, our home in Crowborough, East Sussex, which opened in September, was designed on similar lines and won the 2011 Dementia Care Award for interior design.

Our commitment to helping people with dementia goes beyond our residents and their families. At Heather View, anyone in the community who has dementia, or who has a relative with dementia, can register to use the facilities at the home, which include shops, restaurants, a hairdresser and a cinema.

This kind of commitment saw Care UK pick up two more awards at this year's Dementia Congress - Carole Wardle, Deputy Regional Director, won the Dignity in Care Award, while Elaine Carruthers, Manager of the Orchard Day Centre, which offers 24/7 care and respite services to people in Surrey won Best Manager in a Community Based setting. Investing in people, expertise and excellent new homes means that we can offer our residents the best service possible.

Chartered Society of Physiotherapy

Please note that here we set out the organisation's plans to deliver better outcomes for people with dementia and their carers between October 2010 and 2014, and below each bullet point what progress has been made in the first quarter (October 2010 to February 2011)

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 Chartered Society of Physiotherapy 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.

Progress: We are liaising with the Colleague of Occupational Therapist (COT), namely Karin Tancock and will be arranging meetings, with the aim to produce a resource by December 2011

- In partnership with CPMH the Society 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.

Progress: Have arranged to meet with the Chartered Physiotherapists in Mental Health (CPMH) to discuss taking this work forward

- The Society 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.

First Quarterly Progress Report 2012

The Chartered Society of Physiotherapy has nothing to report for the past quarter

Dementia Adventure

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

- Provide a range of nature based adventures in the UK for people living with dementia and to share these publicly to help promote a better understanding of what it means to live well with dementia
- Provide training and support to staff in care and hospital settings which includes nature in creating supportive, thriving and enabling environments
- Support staff working in organisations which have a primary focus on nature conservation, travel and tourism to actively include people living with dementia in their provision, services and planning
- Carry out more research related activity specifically developing the evidence base for the benefits of green exercise and dementia
- Provide training to increase the uptake of direct payments for people living with dementia
- Expand the reach of our website, in collaboration with partner organisations to continue to challenge the stigma surrounding dementia

First Quarterly Progress Report 2012

The Dementia Adventure has only just joined the Alliance so have nothing further to report for the past quarter

Dementia Advocacy Network

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

- Provide regional networking events to enable advocates to share good practice and increase learning experience.
- Provide planned training programmes and commissioned training for independent advocates to increase their skills and knowledge.
- To share good practice through our events and our website.
- To raise awareness of dementia and dementia advocacy through our trained advocates and taking part in national events, contributing to journals.
- To work with other national partners to raise awareness of dementia and the role of advocacy.
- To increase awareness of DAN to a wider market e.g carers, health and social care professionals, public.
- To identify specialist groups to work with e.g people with learning disabilities, minority ethnic communities, statutory advocates.
- Explore funding opportunities for DAN and support individual schemes in their search of funding.
- Demonstrate the difference an independent advocate makes to a person with dementia through collating advocacy stories.
- Looking for ways to evidence the wider impact of independent advocacy.

First Quarterly Progress Report 2012

- Held two networking events, in London and Bristol, for independent advocates. People updated on current policies affecting people with dementia and discussion on non-verbal communication skills to promote good practice. 29 people attended.
- 4 training sessions held in London and Leeds. 25 people received training in communication skills, dementia advocacy, understanding the carer's perspective.
- Our website provides resources in understanding dementia and good practice in advocacy for people with dementia. An average of 500 people per month are visiting our website to access our resources.
- Collated 16 stories of advocates making a difference to the lives of people with dementia. Publication to be released in spring 2012. Potential tool to increase awareness and understanding of the role of advocacy.
- Accepted by Life Story Network for their project 'Your Story Matters' – to deliver training to advocates in Life Story Work and Making a Memory Book with someone with dementia. Training to take place in spring 2012. Potential of 500 life story books. Increased skills for independent advocates.

Dementia Services Development Centre

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 on line library

First Quarterly Progress Report 2012

- In the past quarter we have continued to seek funding for projects which allow us to offer free or reduced cost publications, places on training and degree courses, and information sessions. As a result, we can get our message out to as wide an audience as possible
- Publications like 10 Helpful Hints for Dementia Design at Home and 10 Helpful Hints for Carers, which are full of sensible advice, are given to family carers at sessions funded by Comic Relief, which we are running in Scotland initially, hoping to attract funding to extend it more widely.
- The Best Practice in Dementia Care training programme for healthcare support workers in hospitals and care homes has been extended with the launch of the programme for domiciliary care workers, and this is being rolled out throughout the UK.
- Improving design of care environments is always high on our agenda. We continue to offer paid consultancy but also free information and opportunities to visit our Design & Technology Demonstration suite. Access is being further extended through the development of a Virtual Care Home, due to be launched on 20 March on the DSDC website, which will demonstrate principles of good design by means of clickable room settings. Anyone, anywhere will be able to visit (virtually) and get ideas for improving environments for care.
- In terms of staffing, we have appointed a new post of Training Officer, and we are currently recruiting a Chair in Dementia Research.
- Internationally, we are working with Hammond Care in Sydney, Australia on a number of publication projects, and planning an international conference to be held in June 2012

Department of Health

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

- 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 NHS 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 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; and 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 medication, 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.

First Quarterly Progress Report 2012

During the period November 2011 – January 2012, the Department of Health has made further progress in a number of the areas set out in its Action Plan.

- The Operating Framework for the NHS in England 2012/13, published on 24 November 2012, sets out a systematic set of actions relevant to dementia care which will require organisations to work together. These include:
 - commissioners should ensure that providers are compliant with relevant NICE quality standards and ensure information is published in providers' quality accounts;
 - commissioners should work with GP practices to secure ongoing improvements in the quality of general practice and community services so that patients only go into hospital if that will secure the best clinical outcome;
 - ensuring participation in and publication of national clinical audits that relate to services for older people;
 - initiatives to reduce inappropriate antipsychotic prescribing for people with dementia to improve quality of life with a view to achieving overall a two-thirds reduction in the use of antipsychotic medicines; and
 - improving diagnosis rates, particularly in the areas with the lowest current performance.

PCTs will also be required to continue to work with their local authorities to publish dementia plans which set out locally the progress they are making on implementing the National Dementia Strategy.

- The NHS Operating Framework 2012/13 also announced the Dementia CQUIN goal to improve awareness and diagnosis of dementia in an acute hospital setting. The new national goal will be measured by three indicators relating to the screening, risk assessment and referral for specialist diagnosis of people aged over 75 who are admitted to hospital. DH will be publishing guidance to support the CQUIN goal shortly.
- The NHS Outcomes Framework 2012/13, published on 9 December 2011, includes a placeholder on enhancing the quality of life for people with dementia. A placeholder represents a commitment to developing an indicator in this area, recognising that this may take time.
- The Department of Health report *Innovation, Health and Wealth*, published on 5 December 2011, emphasised that without the provision of better support for carers of people with dementia, such as the provision of carer breaks and access to a range of psychological therapies, an increasing number will be unable to continue caring and pressure on the health and care system will continue to grow. The report therefore emphasised that the NHS should ensure that a range of these psychological therapies should be commissioned and made available in line with NICE-SCIE guidelines.
- The Department has worked with the General Medical Council (GMC) to refresh the GMC's prescribing guidance for doctors. The GMC has consulted on draft guidance which specifically includes the issue of antipsychotic prescribing and expects to publish the finalised version in 2012.
- The national audit to measure progress towards the goal of achieving a two-thirds reduction in prescribing of antipsychotics for people with dementia is underway and the NHS Information Centre will publish its report in July 2012.
- A dementia awareness campaign, which had previously been piloted in the Yorkshire and Humber and North West NHS regions, was rolled out nationally during November and December 2011. The campaign focused on persuading people to seek an early diagnosis where they had concerns about the possible onset of dementia.
- The Department has commissioned a range of projects on the dementia workforce, covering both training for health and social care staff and training and support for family carers. Two DH-funded education and training projects, the Life Story Network's "Your Story Matters" project and National Museums Liverpool's "House of Memories", were launched in November 2011.

- In December 2011 the Department appointed a permanent project lead for the UK-led contribution to the EU Alcove project on dementia. Alcove is a joint action funded by the European Commission and made up of 30 partners from 19 member states. The UK work programme will continue until March 2013 and involves:
 - an assessment of national recommendations for the diagnosis of dementia in order to access to a common definition with associated operational criteria; and
 - an assessment of health care systems for dementia early diagnosis and evaluation of their implementation, in order to formulate recommendations for improving early diagnosis.

- In November 2011 the final five teams were selected for the national innovation challenge *Living well with dementia*, which is being taken forward by the Design Council in partnership with the Department of Health. The successful teams were each given an R&D grant to develop working prototypes and business models for their proposed solutions

English Community Care Association

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 Dementia Strategy
- Develop an innovation exchange with SCIE 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 (CQC) to inform their regulatory role in ensuring this model is delivered

First Quarterly Progress report 2012

The English Community Care Association has nothing to report for the past quarter

Find

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

1. Find will continue to manufacture and promote our innovations of the last 5 years and to prove and improve the importance of simple, well designed physical solutions to creating an enabling environment.
2. We will pursue additional, unique product developments which turn theories into their physical manifestations and makes them widely and readily available.
3. We will continue to develop relationships which enable us to combine our technical aptitude with experts' knowledge, research and feedback to ensure our solutions are as effective as they can possibly be.
4. We expect Find to continue to sponsor awards which promote and reward individuals commitment and endeavour in the field of dementia care.
5. We will focus on bringing to market brand new products which support nutrition, new lighting technology which enhances the care-environment in a variety ways and develop the use of images for reminiscence and way-finding.
6. We are developing collaboration strategies with charities to play our part in supporting them to deliver their benefits.
7. Following on from the successes we have had in the care home setting, we are developing further products to be appropriate for the domiciliary setting such that the benefits can be applied at the earliest opportunity.
8. We will support more 'trainers' to share knowledge about how physical adaptations of the built environment can deliver benefits on so many fronts to all stakeholders.
9. Find is a key partner in developing the Butterfly Scheme which enables people with dementia (suspected or diagnosed) to be discretely identified as having specific needs when they are going into hospital.

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Find has just joined the Alliance so has nothing further to report for the past quarter

Four Seasons Health Care

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 2 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 i.e. 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.

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What we have achieved over the past 12 months.

- We continued 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 and most homes have a dedicated Dementia Care Mapper.
- We have provided a 1 day 'Caring for Residents Living with Dementia' Course to 1748 staff members who work within our dementia care units/homes this year

- We have delivered Resident Experience training on a 'Roll Out' programme to our homes and trained 111 staff to deliver this internally.
- We have devised and delivered be-spoke training sessions to our staff on different topics such as Mental Capacity Act, Activities, and Nutrition etc.
- We have reviewed the PEARL criteria and it has now extended to 152 criterion and it has also been aligned to latest government recommendations i.e. National Dementia Strategy as well as the CQC outcomes.
- Policies and guidelines within our Dementia Care Manual have been reviewed and added to and these continue to support the PEARL criteria.
- We continue to update the knowledge of the Dementia Care Team to enable our staff within the Company to share our knowledge.
- We 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.
- There are currently 50 homes accredited with PEARL.
- We have introduced a Platinum level for those homes who have achieved Gold.
- DCM is being utilised within the PEARL homes particularly a minimum of every 3 months to help develop care plans and improve levels of wellbeing
- We have developed an e-learning package to cover most of the theoretical underpinning knowledge to care for a person living with dementia and this is now accessible to all staff and has been completed by at least 80% of our staff across the Company
- We have developed a 12 month action plan to assist homes in achieving PEARL as well as developed an induction pack for new employees working within our dementia care homes that is aligned to the Skills for Care dementia modules.
- We have worked with individual homes across the UK and interviewed staff and relatives listening to their comments and suggestions. As a company, we also conduct an annual Customer Survey
- 3 hours every 6 weeks at our Dementia Services Team Meeting has been dedicated to new learning to help us to develop and enhance our knowledge in the field of Dementia
- We have been collating data to record the many benefits of PEARL which have included a reduction in anti-psychotic medication, falls and the number of distressed reactions.
- Four Seasons has won 2 awards, Dementia Care Home of the year and Dementia Care Home Manager of the year in 2010 and we have been finalists for 4 awards to date this year within the team, along with several finalists within the Care Homes.
- We have devised and developed a PEARL pathway programme to assist homes in reaching a quality standard across the organisation in readiness for the full PEARL programme..
- We have held 8 dementia conferences throughout the UK for all our Care Homes to ensure quality standards are maintained.
- A member of the team has spoken at a National Conference in South Africa in October 2011.

- Two team members presented at the National Dementia Conference in Liverpool (2011).
- All team members attended the Dementia Care Congress in Liverpool October 2011
- We have continued to roll out the PEARL project with 60 homes joining in September 2011.

What we have planned for 2012:

- In January 2012 we expanded the Dementia Services team to include 1 extra Project Manager and 2 new Dementia Quality Advisors so we now have 10 Dementia Care Clinicians in the team
- One member of the team is presenting at the International Alzheimer's Conference in London.
- One member of the team is presenting at the Community Care Conference
- One member of the team is presenting at the Royal Society of Medicine Conference.
- One of the Dementia Care Team is currently undertaking a Post Graduate course with Bradford Dementia Group.
- We will continue with the PEARL roll out with 60 Care Homes joining in March 2012 and a further 60 will join in December 2012.
- We will continue to review PEARL and the criteria to ensure it is current and reflect the needs of our resident and staff.
- We will continue to deliver and review the training needs of our staff to ensure training is current and beneficial.
- Members of the Dementia Care Team will continue to expand on their knowledge and share this information.
- We will be introducing an additional e-learning module on Dementia that will be accessible to all staff.
- We will be working in partnership with Boots to ensure all our residents who are prescribed anti- psychotic medication will receive a full medication audit and advice on the possible reduction or discontinuation of medication where it is deemed appropriate
- We will continue to collect data to record the benefits of PEARL.
- We will continue to use Dementia Care Mapping and provide support and mentorship for existing Dementia Care Mappers.

Independent Age

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

Independent Age is currently working to a strategy of influencing the new government to take forward the care funding and reform agenda, and is a founding member of the Campaign to End Loneliness. We incorporate dementia into these pieces of work by:

- ensuring that a funding solution takes into account the burgeoning numbers of people who will be living with dementia by 2014 and beyond
- Researching and promoting the use of befriending and other solutions to loneliness, which includes people with dementia and their carers.

First Quarterly Progress Report 2012

Independent Age has nothing to report for the past quarter

Hft

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

- To offer support to older carers in the community who are caring for ageing (with or without) dementia people with learning disabilities
- To work with local authorities on developing specialist services for people with learning disabilities and dementia
- Continue to develop our staff in supporting people with learning disabilities and dementia
- To improve communication with general practitioners to raise their awareness of learning disabilities in order to provide better services to those on the dementia pathway.
- To share our good practice with other providers
- To gain a quality mark for our services

First Quarterly Progress report 2012

To offer support to older carers in the community who are caring for people ageing with learning disabilities (with or without dementia):

- Hft Cornwall Domiciliary Care provide indirect support to older parents/carers tailored to the individual need.
- Hft Kingston work with many people living in the local community and when they recognise that a carer may be in need of additional support they refer this on to the local social work team in the borough.
- Through the 'enquiries' process at Hft Arden Vale we are receiving calls from ageing carers and are providing information on how to seek support services and who they should contact within their local social care team. We also offer advice on speaking to Hft's Family Carer Support Service.
- As part of case management in Hft Sheffield they support a family with an older parent with dementia and link in with older people services to access support for her and her family and have previously supported the family of an individual who attends 'day services' who has a diagnosis of dementia. This has now reduced since the individual has moved from home into nursing care.

To work with local authorities on developing specialist services for people with learning disabilities and dementia:

- Oxfordshire Social Services is providing training for provider staff teams who support people diagnosed with dementia which Hft have accessed for our staff.
- Our Kent Service has developed existing services for people with LD and dementia and are continuing to work with the local authority whilst they look at the potential to set up a new service.
- Hft Arden Vale continue to attend local provider forums and events to keep informed about what services the local authorities are seeking to commission.

- Hft Gloucestershire are reviewing services provided at one of their locations and as part of this review they are working with Gloucestershire social services about providing specific services to people with dementia.
- Hft Leeds as part of their relocation of a large residential service ran out training around dementia which they invited local authorities and CPN's to.
- Hft Anglian are in the process of developing one of their existing locations into an Ageing person/high physical support needs service, for adults who also have a learning disability. This is an identified need not just within the region externally but also internally as a means of supporting the people we support throughout all stages of their lives. Including getting older and/or having dementia.
- Hft Wirral meet monthly with colleagues in the LD team, this helps them to plan for the support people require at present or in the future. They meet quarterly with commissioners in Cheshire and discuss as an agenda item
- Hft Sheffield, via various networks and forums, check regularly with the local authorities on what their priorities for commissioning are.

Continue to develop our staff in supporting people with learning disabilities and dementia

- Cornwall Short Breaks service is about to implement in-depth training for the staff team.
- A Service Manager in Hft Kent has developed a hand book to give staff guidance on supporting individuals with dementia.
- At Hft Kingston staff are trained in dementia awareness so that they can recognise when an individual is starting to show early signs of dementia and then they can work with the community health teams to make a referral for diagnosis and support.
- Hertfordshire Social Services offer free training to providers which looks very detailed and informative and this is being taken up by Hft Anglian.
- As part of the Gloucestershire Social Services Dementia Training And Education Strategy, Four senior members of staff from Hft Gloucestershire are undertaking the Dementia leadership award programme and implementing, as part of this process, Dementia link workers within the service
- Staff at Hft Arden Vale have received specific training on supporting individuals diagnosed with Dementia through Hft courses and they have developed this further within individual services to create a more personalised approach for the individual person. This training has included staff development around End of Life Care Planning, support on overcoming mobility problems as dementia progresses, awareness and training with SALT for eating and drinking, specific sessions around physiotherapy programmes, information and increase knowledge around nutrition and diet, and loss and bereavement for staff.
- Hft Leeds as well as running training for staff in dementia have also planned training around palliative and end of life care they have also provided specific training around moving and handling people and additional on the use of wheelchairs safely

- Hft Anglian have included a lot of development in regards to staff training into their training budget for 2012/2013. This includes specific training on dementia, getting older, end of life care etc.
- Hft Wirral have training in place for staff on Dementia care, supporting individuals at end of their life and other specialist training offered to groups supporting individuals with dementia.
- Hft Sheffield have dementia awareness training in place and further dementia training where applicable. They also use health support teams and other relevant professionals as and when necessary in order to increase staff knowledge and awareness.

To improve communication with general practitioners to raise their awareness of learning disabilities in order to provide better services to those on the dementia pathway:

- Our North Oxfordshire services have been working closely with their GP's to ensure that annual health checks follow the Cardiff Health Check' which is the one recommended so that GP's cover all areas that need to be considered for people with LD. This service is also working closely with local CLDT psychologist and team who are supporting them with baseline assessments where it is suspected that there is the possibility that a person with Down Syndrome has dementia. They are then supporting the service with follow up assessments in order to map changes.
- All Hft services work closely with their local CLDT's to ensure base line assessments are in place for all people with Downs Syndrome and these are monitored and updated on a regular basis.
- Hft Kingston have introduced 'Health Action Passports' to use with GP's and are booking longer appointments to give time for meaningful discussion and help with communication issues.
- Hft Anglian are currently working with Hertfordshire Social Services to ensure that all people with a learning disability over 40 years of age has a baseline dementia assessment in place.
- Hft Gloucestershire have received learning points following a report from the Confidential Inquiry into premature deaths of people with learning disabilities. One action they have put in place to improve GP awareness of LD services is by implementing 6 monthly meetings with the GP practice to ensure better communication. Also that the GP should be actively involved in Mental Capacity assessments rather than just forwarding to CLDT as this could improve GP knowledge when they are more directly involved and take the role as the decision maker.
- At Hft Arden Vale periodic meetings are held with the GP services to see how we can assist and improve our communications for the individuals that are registered, while working closely with the Health Facilitators in locations to assist individuals to have regular health care checks. Sharing with GP recorded observations for a person so we can assist where a person may need to be assessed for dementia screening.
- Hft Leeds are sharing their recorded observations for a person so they can assist where a person may need to be assessed for dementia screening.

- Hft Anglian are in contact with Affinity Trust who have a dementia/learning disability service. The Area Manager is meeting with them to possibly look at shared training and learning.
- Hft Wirral share recorded observations for a people so they can assist where a person may need to be assessed for dementia screening. This is specifically with the CPN's
- Hft Sheffield have been involved through partnership boards with improving the service GP's offer to people with Learning Disability generally.

To share our good practice with other providers:

- Hft Short Breaks Service in Cornwall is working with two people with Dementia and working closely in cooperation with other providers who support the individuals to ensure a continuity of monitoring and support of their condition. For one of the individuals there is not always an up to date care plan available which is an area we intend to improve.
- A Service Manager in Hft Cornwall has been approached by Social Services Commissioning Team to become a 'mentor' to other providers in order to share skills, knowledge and good practice in setting up individualised service which can include those for people with LD and dementia. This 'help' service will also include information meetings run by the manager.
- Hft Leeds is part of a local area learning disability forum where good practice is shared.
- Hft continue to share information and good practice throughout the whole organisation via the Valuing Ageing Network.
- Hft Wirral are part of a local care consortium who share good practice.
- Hft Sheffield do this through various forums including the Complex Needs Forum which the Area Manager attends and includes discussions re dementia.

To gain a quality mark for our services:

- Hft Fallstaff House in Bidford on Avon, Warwickshire have been awarded the Linda McEnhill award presented through the 'Palliative Care For People With Learning Disabilities Network'. The winning Category for 2011 was "Outstanding care of an individual" <http://www.pcpld.org/linda-mcenhill-award/2011-winner/> the comments of the awarding board of judges was '....stood out for the care they gave to XX, one of their residents who developed dementia. The judges were impressed by the way the team did their utmost to keep XX's best interest (rather than their own) at the heart of everything they did. This was not always easy. It involved engagement with a staggering number of outside agencies and professionals (including the funding authority) and with XX's family. The manager and the support team were staunch advocates for XX, and this meant that he was able to be in the place where he felt most comfortable. They showed flexibility, creativity and a 'can-do' attitude. One of the judges commented: 'If I was looking for a case study to use when teaching professionals what is involved in supporting someone really well, this would be it.'

- Hft Derbyshire are currently working with Derbyshire to gain the dignity and respect standard award as part of their dignity campaign.

Housing 21

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

As part of our Corporate Plan (2011 – 16) Housing 21 has set out a number of key areas and challenges including 'enabling a good later life', 'direct customer engagement' and 'dementia expertise'. We will continue to deliver the objectives outlined in response to question 1 (above).

Additionally we will:

- Focus on awareness, education and making more of the resources that are already available to us to achieve mainstreaming of our specialist dementia expertise
- Increase understanding of existing resources and improve access to information on best practice in service delivery and property design
- Create a strategic partnership framework to expand additional service and information options for our customers, staff and carers, both at national and local levels
- Establishment of a dementia design panel to inform future property design and opportunities for improved environments at refit
- Creation of dementia service user and carer focus groups, that will be project specific and focus on all aspects of Housing 21's approach to dementia care. This forms part of our broader approach to customer engagement; ensuring that customers living with dementia are fully represented in customer / community engagement and communications strategies
- Identify and deliver new ways to fund innovative services that demonstrate positive outcomes for people living with dementia and their carers including dementia voice nurses and dementia advisers
- Ensure that in each locality that Housing 21 operates, there is a staff member trained to use talking mats and dementia care mapping techniques
- Creation of a web-based dementia knowledge bank

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2. Establish and validate an accredited dementia training pathway for implementation across Housing 21 services nationally and establish dementia champions locally.
3. Design and deliver learning opportunities for our customers to provide peer support for friends and neighbours
4. Develop a Dementia Quality Approval Mark awarded to services that have evidenced sustained comprehensive delivery of best practice.
5. Carry out research into assistive technology solutions and service innovation for people with dementia

6. Ensure our customer engagement and communication plans are inclusive of people living with dementia and offer opportunities for them to shape and control their services

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- Ensure that in each locality that Housing 21 operates, there is a staff member trained to use talking mats and dementia care mapping techniques
- Creation of a web-based dementia knowledge bank

Housing 21 is committed to promote its role in the Dementia Alliance via all channels of communication and engagement available to us.

Housing 21 is the largest not-for-profit provider of domiciliary care in England and amongst the top five providers overall. We are also one of the leading developers of extra care housing. Additionally Housing 21 has a strong track record as a provider of specialist, award-winning dementia care services, housing solutions and a reputation for ground-breaking research on dementia.

We already produce a newsletter to commissioners and policy makers called 'Care and Dementia Digest'. In the next issue we will ensure that we profile our role within the Dementia Alliance. Additionally we have rebranded our customer magazine 'MyTime' which goes to all 35,000+ of our residents and service users. In a future edition we aim to feature the Dementia Alliance as part of our plans for inclusive customer engagement and raising awareness of dementia.

We have a corporate website and plan to highlight our membership of the Dementia Alliance via this. Equally we have dementia specific news on the website. We also have recently launched corporate Facebook and Twitter Accounts so we will announce our role in the Dementia Alliance via these channels too.

We work with commissioners and partner organisations across England and are committed to raising awareness of the alliance's work with them.

We are a key member of the National Housing Federation (NHF) – the representative body of the Housing Association Sector who are wanting to develop their knowledge and expertise about dementia and are talking to Housing 21 with a view to doing this. They influence and lobby government on behalf of the sector so we would be able to link with them.

Also our communications team have set up a series of meetings with key members of government with an interest in health and social care. Again we can promote the work of the Dementia Alliance via these meetings.

Housing and Dementia Research Consortium

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.

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Having been successful in our application to the Technology Strategy Board's DALLAS (Delivering Assisted Living Lifestyles at Scale) competition, we have continued to be successful in subsequent stages of the competition and are currently part of one of the eight shortlisted communities. The final selections will be made over the coming weeks ready for the programme to commence in Summer 2012.

The HDRC website has been further developed and now contains, within the 'members only' area, descriptions of our priority research questions / ideas

and a members' newsletter, outlining the activities of the HDRC, updated monthly.

- New members continue to be added to the membership database, which now numbers 94.

We have brought together a team of researchers from within the HDRC membership who have submitted a proposal to the NIHR SSCR 4th Wave Call, answering the call research question: How can adult social care and support practice best contribute to the provision of high-quality, cost effective care and support for people with sight loss, or with sight loss and dementia?. Project title: "Developing best practice in social care and support for adults with concurrent sight loss and dementia within different housing settings".

Another HDRC team is working on developing a proposal for submission to the NIHR PHR programme in April, exploring the impact of interaction with the outside community on the health and wellbeing of housing with care residents, with a special focus on those with dementia.

We have conducted a small in-house study of provision for people with dementia within HWC schemes from among the core members. This will help inform future research development.

Jewish Care

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 & 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 be registered with the Gold Standards Framework (GSF) 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 (At):

- 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 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.

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Jewish Care has nothing to report for the past quarter

Life Story Network

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

- Our current project will support the delivery of new ways of working to realise dementia friendly settings and communities, with well trained staff. Life Story is one of the keys to delivering person centred care by placing the individual and their biography at the heart of care and support. It provides support staff and carers with a practical set of tools to help them engage with the real person and see them beyond their illness, disability or diagnosis.

By April 2012 the LSN will:

- Establish a national network of trainers through the facilitation of a managed learning network utilising action learning, coaching and peer support;
- Provide awareness raising and training on Life Story work to 500 people including the Human Rights Act and the legal duty placed on public bodies to be compliant with the Act;
- Achieve sustainable transformational cultural change by engaging with leaders at a corporate level in organisations, to encourage providers to collect robust evidence on the effectiveness of life story work;
- Disseminate learning through a variety of media; and
- Conduct an on-going evaluation of the work with our existing research partner, the Social Policy Research Unit at York University.

In subsequent years the LSN will:

- Further consolidate the support and training offered via the network including directly commissioned work and a programme of webinars.
- If successful with the NIHR research bid we will work with SPRU and partners to develop a strong evidence base for life story work.

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We are making significant progress in delivering the current project, Your Story Matters, which aims to deliver life story work training to 500 people by April 2012.

Introductory courses have been held with a further one planned. Individuals who will train others have commenced their training programme.

LloydsPharmacy

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

- We will continue to support our care homes customers in providing training to care workers in the safe administration of medicines to people with dementia and provide materials to support good practice
- We will continue to provide a range of solutions to help people to remember to take the right medicines at the right time both in the community and care home settings.
- We will support our pharmacy teams to be more aware of dementia and increase understanding of the particular challenges this group of people face through ongoing training and information.
- Where appropriate, we will use existing contractual services (Medicines Use Reviews) to closely monitor medication compliance amongst our patients with dementia, and bring any issues arising to the attention of the GP. This will help more people live in their homes for longer.
- We will develop tools for use in pharmacy to highlight dementia patients and, in support of NICE guidelines utilise these tools to ensure appropriate review of anti-psychotic medicines prescribing in care homes. From October we will be working with our BUPA care home customers using prescribing data from our dispensing systems to implement a specific anti-psychotic medicines review to highlight to care workers and GPs where prescribing for anti-psychotic medication does not meet NICE guidelines.
- We will continue to develop our work with the domiciliary care worker community in assisting with the safe administration of medicines (care plans).
- We will work with Government stakeholders to improve governance and standardise medicines administration recording to minimise risks in this area. We will work with NHS organisations to improve the transfer of care for patients from one setting to another (for example secondary care to residential nursing home).

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LloydsPharmacy is a new member and has nothing further to report this quarter

Local Government Group

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

- 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 LGA programme at an appropriate moment
- Assist in promoting material for councils through website and newsletters

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- The Local Government Group has nothing to report for the past quarter.

MHA

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 locally to our services 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.

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- MHA continue to invest in staff with the delivery of specific training related to caring for people living with dementia. The training is primarily delivered using an e-learning system for all relevant staff during their induction and as an on-going part of rolling training.

- The Person Inside - Dementia Awareness Training continues to be delivered at all homes and schemes caring for residents and tenants living with dementia.
- MHA maintain their commitment to Dementia Mapping and currently have 72 trained mappers across the organisation. A further 30 places are available for the next course which is scheduled for February 2012. The next training course is being prioritised for staff employed at the homes recently acquired and transferred from previous Southern Cross ownership.
- A number of MHA existing trained dementia mappers have been deployed to work in the newly acquired homes as an interim measure prior to the completion of training by their own staff.
- MHA continue to review and monitor standards within all homes and housing with care schemes using an in house standards assessment. This has identified continued high levels of compliance against all standards associated with the utilising of a consistent person centred approach to care.
- The training department have compiled a dementia resource box and are currently working closely with Bradford University. It is anticipated that following further modifications to the current content, the box could be jointly badged by Bradford University and MHA to offer further flexibility when considering appropriate training for staff caring for people living with dementia.
- The pioneering work of using music therapists within MHA homes caring for people with dementia is being expanded to ensure full coverage of the relevant homes recently acquired by the organisation. This expansion will increase the number of homes receiving the service by a further 22.
- MHA are maintaining their commitment to research into care and support for people with dementia with their on going relationship with the Housing and Dementia Research Consortium.
- The work within MHA addressing the reduction of antipsychotic medications in care homes has been extended to include the recently acquired homes. The organisation will be working closely with their pharmacy provider
- Other activity listed in our Action Plan is on-going

Mental Health Foundation

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 (e.g. 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 4 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 on-going project work on mental capacity issues.
- Ensuring that people with dementia are included, as appropriate, in our on-going project work on promoting positive mental health and well-being for the general population, as well as projects tackling more specific mental health issues (e.g. depression)
- 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.

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All four projects have submitted their final reports. These reports, together with a summary of the scheme will be made available in spring 2012 (delayed from last report).

People with dementia are included in the Best Interests Decisions Study (BIDS) that we are doing with Bristol and Bradford Universities. This project is now complete and the research report (*Making Best Interests Decisions: People and Processes*) was published on the 31 January 2012. The report and a lay summary can be downloaded from the Mental Health Foundation's website (go to the Publications page) and includes a section that specifically

looks at mental capacity issues in relation to people with dementia – www.mentalhealth.org.uk/publications/.

The Mental Health Foundation has received a large research grant to undertake research about direct payments for social care from local authority social services for people who lack mental capacity to consent to the payments, because of dementia or learning disabilities. New regulations in 2009 allow for a 'suitable person' (e.g. a trusted family member) to manage the direct payments on the person's behalf. The research will investigate how well these new regulations are being implemented. The research is well under way and several local authorities have agreed to participate.

The Mental Health Foundation has now secured funding for an exciting new project, working with Housing 21, to run self help, peer support groups for people with dementia living in extra care and sheltered housing in London. We are currently advertising the post of group facilitator to run the groups which we hope will start in the next 2-3 months – more details of the post can be found at (closing date 20 February): <http://www.mentalhealth.org.uk/about-us/vacancies/>

No specific activity to report but the mental health strategy (*No health without mental health* – DH, 2011) does cross refer to the National Dementia Strategy and the Public Health Outcomes Framework (DH 2012) includes dementia in its outcomes.

No specific activity to report although we hope that our booklets about dementia for people with the diagnosis (*Still going strong*), family carers (*Becoming a carer*), and children and young people (*The milk's in the oven*) provide useful practical advice for these groups. All are available to download for free from <http://www.mentalhealth.org.uk/publications/>

The mapping survey is almost complete and 82 groups and 15 individuals responded to the questionnaire. Innovations in Dementia are doing a number of follow up interviews with groups that responded and this is almost complete. Key findings will be made available at two events for people with dementia in London (21 February) and Stockport (13 March) that the Alzheimer's Society is helping to organise, and published in a report by the JRF later in 2012. We have begun to build a map showing where these groups and projects are which you can see at: <http://www.mentalhealth.org.uk/our-work/research/research-projects/dementia-engagement-and-empowerment-project/?view=Standard>

Two programmes are being run and the evaluation has begun – it will be complete in April/May 2012.

My Life SPG Ltd

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

By the end of 2012 we will:

- Recruit new partners to enable Dementia Life undertake an ongoing programme of network development to expand the breadth and depth of connections and influence. A priority is to engage with the changing national and local commissioning structures within the new NHS and social care environment. With the intention of making our product more accessible to those who can benefit from it, we aim to start a dialogue with key influencers, Health and Well-being boards, Clinical Commissioning Groups and their shared services as well as existing procurement hubs to gain product approvals and to understand and influence opinion and strategy behind the developing procurement pathways.
- Achieved a significant increase in the organisations that are able to provide the benefits of DRTS to their patients and carers. We will continue to build and expand our network of customers, clinical professionals and users with a focus on compiling and sharing qualitative and quantitative evidence behind the stories of benefits our product brings to people with dementia, their carers.
- Have led a pilot site study with a care provider to demonstrate how to successfully implement DRTS into a care setting and disseminate the approach and results.
- Attended a comprehensive programme of conferences and communication events to showcase the product benefits to a wider and growing audience of opinion leaders, clinical professions and other supporters.
- Tested and be ready to launch the next release of the software that will incorporate many additional features in response to user feedback including tools that support the diagnosis of dementia.
- Add a web based DRTS application to the portfolio that can be downloaded and used on a wide array of touch screen devices already owned by individuals and organisations. A web based version will increase the accessibility and availability as well as being simpler and less expensive to maintain and update.

Beyond 2012 we will:

- Be supporting collaborative projects involving academic, third sector and clinical partners which expand the knowledge and understanding of the benefits and cost effectiveness of DRTS.
- Have greatly expanded the communication capability so that people can use the software to communicate with family and friends world wide.

- Add new languages to DRTS so that the product is bringing benefits to people from an array of nationalities.
- Have a well advanced programme of work developing the capability to share patient safety information with providers and professionals for the purpose of supporting and protecting vulnerable older people.
- Have significantly improved the perception that there is little that can be done to improve the quality of life for people affected by dementia and changed the belief that those with cognitive impairment cannot use technology

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We have expanded our number of NHS sites with excellent results from all and we have sponsored and attended dementia workshops at local NHS Mental Health Trusts. We are completing clinical trials with many of our NHS sites and will be publishing the outcomes of these once complete.

We have continued to expand our network of customers working with some large organisations to build bespoke software solutions using DRTS.

We continue to work with our key partners to strengthen our product in order to ensure we develop our software to ensure it can provide the most effective support to carers in engaging and communicating with people.

Our user community continue to share with us their success stories and we publish these wonderful moments through facebook and twitter which allows us to communicate with a wider audience and show that quality of life for people with dementia can be provided. We have launched a monthly newsletter which helps us share the stories across our user community and helps carers identify best practices.

Our list of events to be attended in 2012 to help promote awareness is growing and we are publishing new case studies. We are supporting 'the house of memories' reminiscence training programme developed and delivered by National Museums Liverpool, through the kind support of the Department of Health.

Our pilot of our new lifestory module is almost complete with amazing results; using personal photographs to upload and tag to a digital life story book is helping aid reminiscence sessions. We will be launching lifestory to the market place in the coming weeks.

Professor David Jolley is working with us and a team of healthcare professionals to design cognitive measurement and monitoring software. We hope to have this included within our software by the summer of 2012.

We continue to work on the development of our software in additional languages and as a web based application to help increase availability of DRTS.

National Care Forum

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

The NCF has developed 'best practice guidance on dementia care' for our members. We have also led a study tour to Denmark and Sweden in 2010 to look at best practice models and learning from other countries.

We will continue to work in partnership to influence the quality of care and support provided to people with dementia (and their carers) by:

- Promoting awareness and best practice to members through information, guidance, events and activities
- Supporting dementia champions
- Building on our relationship with SCIE and resource initiatives such as the Dementia Gateway
- Utilising our international networks to ensure learning on best practice from around the world is shared
- Working with the National Skills Academy for Social Care to inform the leadership programme to support dementia care services
- Leading work with the Department of Health to improve medication management in care homes
- Completing joint work with NCPC on supporting people with dementia at the end of life
- Ensuring that best practice from our members is disseminated and shared

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The NCF issues a weekly News letter to all members. This has included the latest news in relation to the NDS Strategy and developments across the sector. It also captures best practice examples re innovation which members share.

NCF continues to be represented on the NDS IRG by Sharon Blackburn (Policy and Communications Director). Outcomes from these meetings have been communicated to members. Next meeting is to take place on 2 May 2012.

- Sharon Blackburn also works on behalf of NCF with the NCPC as National Advisor on Older People. NCPC continue to produce learning materials and have organised conferences regarding dementia.

NCF holds an Annual Managers Conference. It is attended by c 200 Managers and senior staff across the NCF membership. Dementia services are always an integral part of the event. This took place in November 2011.

- NCF held its 8th Annual Conference on the 10/11 May 2011. A workshop on the work the Dementia Action Alliance took place.
- An entry has been written for inclusion in the NCF Annual Review Book which is given out at the NCF 9th Annual Conference due to take place on the 22 and 23 May 2012. The Annual Review is also circulated to a wide range of key stakeholders.
- NCF AGM was an opportunity for members to meet at an NCF member site to see firsthand dementia services and explore care models and the lived environment.

Dementia Services remains a key topic for the NCF Practice Forum.

- The Order of St John Charitable Trust (an NCF member) now has an Admiral Nurse. NCF supports and promotes the Admiral Nurse approach.
- NCF as members of the European Association of Homes and Services for the Ageing (EAHSA) (Sharon Blackburn is a Board Member) are engaged in tour and conference participation/planning- Dementia continues to be a key topic. Likewise NCF are the English chapter of IAHSA.
- The IAHSA Global Ageing Conference took place in Washington DC in October 2011. Sharon Blackburn on behalf of NCF presented at the conference. Of the 2 presentations made one was an education session based on the My Home Life Movement concerning 'Living alongside Dementia'- perspectives from residents; relatives and staff.
- NCF have been successful securing funding from the DH to improve medication management in care homes. The project was launched in March 2011. On November the 1st a number of proto types were launched by Paul Burstow Care Services Minister. A second phase to the project is anticipated dependent on further funding.

NCF has reviewed the Skills for Care Dementia modules for the new QCF. Some of NCF Members Activity(This is just a sample.....) in relation to Dementia Care:

1. **Accord Care and Support** are now offering Dementia specific Cafes.
2. **Avante Partnership** are working with Canterbury Chrsitchurch university regarding Dementia Care
3. **Central and Cecil** – Lead Dementia Care Champion across the Group; Dementia champions at each care home. Supported by quarterly meetings. They are joining this work up with the work of the Dignity Champions. They are piloting MyAmego an Assistive Technology system that allows people with dementia to be more independent. They have a local dementia action strategy and action plan. They are using the PEACH philosophy which supports the NDS. People using services and their carers/staff can give feedback through the 'Star Experience'.
4. **CLS/Belong** – are implementing new models of care in their Belong villages. Using design and the environment to enable people with dementia to have more personalised services. Kerry Fisher was the recipient of the Lifetime Achievement Award in Dementia Care at the UK Dementia Congress .

5. **HICA Group** – have created new care and housing solutions for people with dementia that are innovative and personalised.

NAPA: Living Life

Our plans as an organisation to respond to these challenges between now and 2014?

NAPA publications and training courses emphasise: the importance of one to one activities; creating an environment which offers opportunities for things to talk about and do; and making the most of shorter spontaneous activities with people in the later stages of dementia. We will continue to disseminate these resources to our members and others. We aim to increase our membership by 30% to 4000 members by the end of 2014, ensuring our messages are reaching a wider audience.

The NAPA Activity Toolkit promotes activity as being everybody's job including nurses, care workers, maintenance, catering and domestic staff and family members. We aim to sell 1000 guides and DVDs in the next two years. NAPA's resources support a whole day approach to activity which includes seeing routines and tasks in the day as potential experiences to be enjoyed, supported by the right attitude and approach from staff. We will continue to publish articles which challenge institutionalised practice and inspire creative approaches.

Our new Living Life with relatives and friends bulletin will be disseminated widely to families offering support and ideas for one to one and small group activities in which they can get involved.

NAPA will be delivering and promoting a range of new training courses within the new Qualifications Credit Framework, which we will ensure includes guidance on activities which are accessible and meaningful to individuals with dementia.

NAPA plans to be a key player in a 'Go for Gold' initiative with the British Heart Foundation and other partners to tie in with the Olympics in 2012. This will promote the importance of physical activity for older people including people with dementia. This initiative will run throughout the year and will offer inspiration, ideas and goals for new physical activity ideas, particularly in care settings for older people.

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NAPA is a new member and has nothing further to report this quarter.

National Council for Palliative Care

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' national conference on 8th December 2010
- Develop accredited training with the 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.

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We were proud to host a roundtable discussion at the first ever Dementia Action Alliance (DAA) conference on 29th November 2011. Alice Fuller, NCPC's Policy & Parliamentary Affairs Lead, led an interactive session based on our *Difficult Conversations for Dementia* work and wider materials. She asked participants to reflect on how much they'd thought about dying, death

and bereavement, what plans they'd made and whether they'd discussed their wishes with their friends and family. Participants then brainstormed issues relating to end of life care for people with dementia, with issues around mental capacity and advance decision making particularly highlighted. Each participant took away a copy of *Difficult Conversations* and a pledge to do three things as a result of the discussion, as well as an invitation to join the Dying Matters coalition.

We held our sixth annual conference on dementia and end of life care in partnership with Alzheimer's Society and Dementia UK on 12th December 2012. Interactive theatre and good practice workshops were accompanied by speeches from Professor Alistair Burns and the former Secretary of State Rt. Hon. Hazel Blears MP, who shared for the first time her family's moving experience of dementia. Alzheimer's Society's Chief Executive Jeremy Hughes identified his top ten priorities and provided the take-home message of the day: "we cannot afford *not* to talk about end of life care in dementia."

Our Dementia Group, a cross cutting group of representatives the dementia, social care, housing and palliative care organisations, met on the 23rd November to discuss next steps and its role joining up of the range of work underway. Dr Liz Sampson, member of the group and Senior Clinical Lecturer at the Marie Curie Palliative Care Research Unit and Martina Kane from Alzheimer's Society's presented on their respective work exploring palliative care for people with dementia. The group is seeking funding to continue its work into 2012/13, and is particular keen to expand work in the hospital setting.

The January 2012 edition of our monthly e-newsletter *Policy Roundup* included a spotlight of dementia, highlighting the Health Secretary Andrew Lansley's commitment at the DAA conference to producing a mid-term review of the Dementia Strategy, the launch of the All-Party Parliamentary Group on Dementia inquiry into diagnosis rates, SCIE's new online dementia resources and other developments.

As part of our response to NICE's draft Quality Standard for End of Life Care we highlighted the need for the document to acknowledge that people with dementia will need to plan ahead of the last twelve months (the remit of the Standard) and to link to the dementia strategy. Our recommendations were incorporated into the final Quality Standard published by NICE in November 2011.

We ordered a reprint of *Difficult Conversations for Dementia*, as 3,000 copies had already been distributed by the end of 2011.

We created a new page on our website to update on our dementia work:
www.ncpc.org.uk/site/dementia

National Development Team for Inclusion

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

- Through a project being carried out with Innovations in Dementia and local organisations and people in four areas, we will work to build Circles of Support for 40 people with dementia between 2011 and 2014. Through this project we will investigate and communicate how this type of approach can help people with dementia and their carers to live more positive and inclusive lives within their communities.
- We will continue to develop and deliver new projects which will result in improved outcomes for people with dementia and their carers.
- We will work with organisations and agencies in health, social care and other sectors to improve understanding about and tackle stigma and negative attitudes towards dementia, by highlighting where these exist and developing strategies to deal with them.
- We will also work with the above organisations (particularly those delivering mental health services) to support them to deliver age equal services through using Age Equality Toolkits and other resources developed by NDTi to achieve equality across all protected characteristics outlined in the Equality Act 2010.
- We will continue to involve people with dementia and their carers widely in our work, ensuring that their voices are heard clearly and guide the development of our programmes and approaches.
- We will communicate our learning, particularly about what can be done practically to enable people with dementia to live well, with real choice and control within their lives. Learning will be shared through the range of communications used by NDTi including reports, published articles, leaflets, NDTi website, press releases, social media and at conferences and other events.
- Through the above, we will contribute towards greater understanding of and tackling stigma and fear around dementia by highlighting the aspirations, achievements and capabilities of people with dementia.

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- We have, along with our partners Innovations in Dementia, continued to develop and implement the Circles of Support for People with Dementia project over the past quarter. This has involved:
- Setting up and running the first Circles of Support with people with dementia, and their families and friends, within the project.
- Holding workshops in each of the 4 pilot sites to engage people in the project and train people in using the person centred approaches and tools which have been developed for the project.
- Publicising the project more widely within each of the pilot sites, through local media and by making links with local organisations and groups within the areas.

- Discussing, with other national organisations, their potential involvement in this project or the possibility of jointly developing a Circles of Support approach for the people they work directly with.
- We have also been delivering or involved in other initiatives designed to increase the voice, choice and control of older people with high support needs, including those living with dementia. Examples include:
- Disseminating the findings and outcomes from the two year South East Regional Initiative (funded by the Office for Disability Issues) to embed opportunities for independent living for people living in care homes and those at risk of moving into care; and working with the South East Regional Forum on Ageing to roll these out across the region.
- Delivering a series of 5 masterclasses on volunteering in later life with CSV, including a focus on increasing access to volunteering opportunities for older people who need support.
- Undertaking fieldwork in 4 study sites to find out about older people's access to and experiences of support based on mutuality and reciprocity, for example Shared Lives schemes for people living with dementia.

National Institute for Health and Clinical Excellence

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/latelife

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- Workshops were held last autumn to guide the development of the quality standard for Care of people with dementia. Please see the website for details.
<http://www.nice.org.uk/guidance/qualitystandards/socialcare/home.jsp>
- Professor David Croisdale-Appleby has been appointed as Chair for the Care of people with dementia Topic Expert Group.
- Consultation on the scope will occur this quarter and for the draft standard from August 2012.

References to implementing the NICE/ SCIE guideline on dementia are made in the December paper Innovation, health and wealth, and dementia and its impacts are recently announced in the Public Health Outcomes Framework. NICE will highlight its resources available to help local organisations to do this and learn from others over the next quarter.

NHS Alliance

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.

First Quarterly Progress report 2012

We have a major conference on ageing coming up:

<http://www.collegeofmedicine.org.uk/annual-conference-2012>

The UK population is growing in size and age. Between 1985 and 2010, the number of people aged 65 and over increased by 20% to 10.3 million; in 2010, 17% of the population were aged 65 and over. The ONS projects that by 2035, the number of people aged 85 and over will reach 3.6 million, 2.5x the figure in 2010 and accounting for 5% of the total population; and the population aged 65 and over will account for 23% of total population.

Population ageing brings benefits as well as challenges to society, from a policy, economic, social and healthcare perspective to name just a few. Healthy ageing is the focus of the College of Medicine's 2012 Annual Conference. As the ageing population will need to be cared for with comparatively fewer resources, a completely new perspective on health and ageing will be required to meet this challenge.

The College of Medicine is uniquely-placed to explore the necessary answers. These answers will need to encompass mind, body and spirit and the different perspectives of scientists, clinicians and patients. New solutions will need to encompass therapeutic medicine but also extend to self care and healthier communities if we are to create a sustainable health service.

The answers will begin keeping people younger (and healthier) longer and then, when they do age ensuring that they remain as active, well and fulfilled as possible.

NHS Confederation

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

- 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.

First Quarterly Progress report 2012

Further to receiving written evidence from around 40 organisations, the Commission on improving dignity in care for older people has now completed three days of public hearings with evidence from around 25 organisations or individuals.

The Commission will launch a public consultation on its draft report and recommendations in early 2012. Organisations and individuals across health and social care, as well as older people's representatives and older people, their families and carers, will be invited to respond.

The findings and recommendations are due to be published in spring 2012.

More information can be found at:

<http://www.nhsconfed.org/priorities/Quality/Partnership-on-dignity/Pages/Commission-on-dignity.aspx>

Our website provides links to the latest publications and policy documentation on dementia issues.

- Key publications are summarised and included in our fortnightly 'Health Policy Digest' which is circulated to all our members. This also includes links to the full publication.

Orders of St John Care Trust

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

- OSJCT recognises the need for a strategic focus on delivery of dementia services. Over the coming 12 months we will review our existing services and identify the key components for our model of care, learning from our experiences to date and the knowledge and research from colleagues at Stirling University amongst other acknowledged clinical and academic experts.
- We will implement an audit process that captures the outcomes of the experiences of those we care for and a system by which this will underpin our ongoing learning and improvement.
- We will continue to listen to the views and opinions of those we care for, their families and friends, and enable them to influence our actions.
- In conjunction with colleagues at The Alzheimer's Society, we will build on our existing training programme and introduce in 2011 the new accredited Champions of Dementia Care Leadership Programme.
- During 2011 we will review all our care environments and include recognised principles of good practice in all refurbishments and new builds, particularly through the use of colour, lighting, acoustics and way finding.
- We will identify ways to both creatively and innovatively improve our existing Homes' environment to support activities of daily living and we will undertake to provide unrestricted access to external space for all residents by 2012.
 1. Longer term goals will be to develop further the range of activities involving arts and music and increase our volunteer network to enhance friendships and lifestyles.
 2. identify ways to raise awareness locally, support carers groups and provide access to resource centres in our homes
- We will continue to work towards our vision of Dementia Care, acting on the information we receive from residents and their families. We will support our staff to achieve best practice through a process that is inclusive of reflection and review.

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OSJCT has completed a restructuring exercise and as an organisation are in the “bedding in” phase in bringing about greater consistency and quality control of its services.

A revised audit tool was made available to all Homes in January 2012 with the opportunity for each home to achieve internal accreditation in dementia care, based on the lived experience of the person with dementia.

Working with the Design Council we are currently exploring different ways to capture the views of residents, staff and relatives in ‘real time’ feedback. The outcomes from this initiative will be shared throughout the organisation.

An evaluation of the Champions in Dementia Care Leadership Programme is currently being undertaken with the first set of cohorts. Following a series of workshops held in the latter part of 2011 all of our homes now have a dedicated Dementia Lead

Following this review in 2011 we are now working towards establishing consistency of best practise across the Trust, particularly with the care environments. This is underpinned through the accreditation in dementia care part of the revised audit tool.

Through our dementia awareness training programmes for staff, the revised audit tool with the opportunity to achieve internal accreditation, the continuing development of our Dementia Leads, the Champions in Dementia Care Leadership Programme, the work towards the consistency of the environment, the continued support from our Trust Advisor and Admiral Nurse and maintaining our close links with external agencies we will continue to seek ways to improve the lived experience of residents and achieve our longer term goals.

Parkinson's UK

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

Pictures to Share plans to continue to develop many more visual resources for people with mid to late stage dementia by 2014.

We hope to develop more links with care providers, the NHS, public libraries and organizations working with family carers to make sure everybody with dementia has the option of benefitting from our resources.

First Quarterly Progress report 2012

Parkinson's UK are working with the Lewy Body Society and have employed a Senior Education and Partnerships Officer, a jointly funded post, who will be starting in post in the later part of February. She will be working on developing and implementing approaches to ensure effective care and support for people with dementia with Lewy bodies, working in partnership with the Lewy Body Society. It will also involve establishing an advisory body for dementia with Lewy bodies that can steer the work of the Lewy Body Society and act as an advisory group within Parkinson's UK, involving expert professionals and people affected. Lastly they will work through the advisory group, develop and implement a business plan to improve treatment, care and support people who have dementia with Lewy bodies, embedding this work wherever appropriate in the relevant function of Parkinson's UK.

Parkinson's UK are also supporting a new research project entitled "Does the drug apomorphine have 'anti-dementia' effects?"

Pictures to Share

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

Pictures to Share plans to continue to develop many more visual resources for people with mid to late stage dementia by 2014.

We hope to develop more links with care providers, the NHS, public libraries and organizations working with family carers to make sure everybody with dementia has the option of benefitting from our resources.

First Quarterly Progress report 2012

In the last quarter, Pictures to Share have developed and launched a new and innovative DVD which aims to provide an alternative to inappropriate television for people with mid to late stage dementia.

In the dementia care industry, television is often used in inappropriate ways and can create more problems for people with dementia. This is partly because of a lack of suitable resources that provide an effective alternative which has been designed specifically to meet the needs of people with dementia. Pictures to Share wanted to address this issue.

Using still images and a musical soundtrack with sound effects, the new Pictures to Share film is in line with recommendations discussed in the American research reported in the Journal of Applied Gerontology 2009 28:638 (Television Viewing and People with Dementia Living in Long-Term Care: A Pilot Study. Kate de Medeiros, Erica Beall, Stephen Vozzella & Jason Brandt)

The industry reaction to this new type of DVD has been positive and Pictures to Share are now developing a second DVD using lessons that have been learned from the development and production of the first.

Funding for this innovative development work has been provided by a Social Enterprise Loan from Keyfund with support from European funding. The challenge that Pictures to Share now faces is to pay back this loan funding through sales of the DVDs.

Priory Group

Please note that here we set out the organisation's plans to deliver better outcomes for people with dementia and their carers between October 2010 and 2014, and below each bullet point what progress has been made in the first quarter (October 2010 to February 2011)

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

- All our care homes will be purpose built with the person living with dementia in mind. Every home will have a minimum of 2 trained Dignity Dementia Champions and every member of the care team will be trained to deliver true person centred care

Progress: Our Dignity Dementia Champion (DDC) development course commenced in January 2011 and to date 2 modules have been completed by home managers and one other from each home.

- Our model of enriched care will continue to be at the core of all we do and the 7 Strands of Care That Lead to True Person Centred Care in a Priory House will be our mantra and instilled in every person that provides care and support to people living with dementia and those embarking on that journey. Moving forward,

Progress: This is implemented and being developed via the above DDC

This is also under review via auditing and dementia mapping to ensure implementation, and understanding

- The Priory Group will develop relationships with every member of the disciplinary team, forging community links with them and offering colleagues training and development in dementia care. Always A Last Resort is policy in the care homes and will continue to be utilised in order to prevent over use and reliance on antipsychotic medicines.

Progress: This is being developed at each home. Always a Last Resort is monitored monthly and actioned as appropriate

- The Priory care homes division will continue to be led by a proactive Director of Dementia Services who will lead on best practise initiatives. Full inclusion of people living with dementia and those supporting them through the journey will be another way of ensuring all the homes become centres of excellence.

Progress: I am currently recruiting to the Head of Dementia Services, and in the absence of this person various personnel are progressing our Dementia Strategy

- In terms of regulation inconsistencies, we respond to this through developing a consistent approach to dementia care in all our homes

Progress: Ongoing

First Quarterly Progress Report 2012

Following the integration of the Craegmoor portfolio, Priory have undertaken a strategic review of dementia provision within our Older Peoples Services. The report arising from the review is in draft form. We are in the process of evaluating the findings of the review in order to further develop our action plan.

In the meantime progress with key actions in particular the focus on staff training and development continues

Re:Cognition

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

1. Provide an increased number of GP educational seminars on all aspects of cognitive impairment throughout southern England.
2. Continue to expand the multi-disciplinary team of Consultant with special expertise in cognitive impairment in order to increase services.
3. Evolve the neuropsychology service in order to make it more accessible with a lower price point, faster delivery model and more geographically distributed, through the use of technology combined with specialised neuropsychologists.
4. Introduce and promote an early cognitive health screening package.
5. Increase the availability and accessibility of early assessment and diagnosis centres by opening satellite centres.
6. Continue to meet with GP Commissioning groups to prepare to respond to the anticipated 2012 NHS Tender for early assessment and diagnosis of NHS patients.
7. Provide a cognitive screening service for residents of retirement centres and care homes.
8. Develop and launch and promote a sophisticated cognitive function test for the general public.
9. Increase spending for general the awareness of the need for early assessment and diagnosis.
10. Expand the longitudinal Care Management programme for patients and carers to include: educational, sign posting and planning information; carer support programmes; reminder messaging; monitoring and routine assessment; and assisting in the scheduling and management of care service providers.

First Quarterly Progress Report 2012

Re:Cognition have just joined the Alliance so have nothing further to report this quarter.

Royal College of GPs

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

The revised Dementia Strategy Implementation Plan (Quality outcomes for people with dementia: building on the work of the National Dementia Strategy, DoH 2010) prioritises 4 areas for quality improvements in dementia care. Primary care, and GPs, has key involvement in 3 of these:

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

The RCGP's role will be focused on these 3 areas, initially at a national level, through the work of the RCGP champion for Ageing/Older People (Professor Louise Robinson) via:

i) 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.

ii) BGS 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.

Progress: BGS Care Homes project: Professor Robinson is RCGP representative on this (completion 2011). This project due for completion in spring 2011. Guidance is developed.

iii) 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 DoH 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 Psychiatry, on the prescribing of anti-psychotic drugs in dementia.

First Quarterly Progress report 2012

Dementia as RCGP Clinical Priority: appointment of a National RCGP clinical champion for dementia 2012 -2015.

As stated above Professor Robinson submitted an application to the RCGP in October 2011 to seek RCGP approval for Dementia to become a RCGP Clinical Priority theme. This was successful; interviews for the RCGP National Clinical Champion in Dementia will be in February and the successful candidate announced in March 2012 in time for the next update. Details of their planned programme will be brought to the Alliance in subsequent updates.

Royal College of Nursing

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

- Support and delivery on 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.

First Quarterly Progress report 2012

The RCN launched the '**Commitment to improve care for people with dementia in general hospital settings**' on the 21st September 2011. This has been developed collaboratively with and supported by a range of stakeholders including other royal colleges, and voluntary sector organizations.

The aim is that this Commitment will be used as a guide to support the delivery of dignified care for people living with dementia and their families. It sets out five key ingredients with supporting factors, for promoting a positive experience for people with dementia and their families and for staff to use in making positive changes to care.

SPACE – top five ingredients to support good dementia care

1. **S**taff who are skilled and have time to care.
2. **P**artnership working with carers.
3. **A**ssessment and early identification of dementia.
4. **C**are plans which are person centred and individualised.
5. **E**nvironments that are dementia-friendly.

We are promoting and disseminating the commitment across organisations and encouraging dementia leads to use the principles as a checklist, so that local actions can be developed in support of delivering the commitment.

For further information about the commitment including how to access resources such as pocket guides, posters, pens and mouse mats please see: www.rcn.org.uk/dementia

Supporting increased understanding of dementia for nurses

The RCN has also developed a suite of on-line resources which aims to promote awareness and understanding about dementia and can be located on the link above.

The RCN Dementia resource, offers a range of information about dementia in general and links to other resources that will help promote better understanding of the needs of people with dementia, their families and carers. It points to some of the most recent information sources available on dementia and includes:

- information to support understanding dementia
- resources for supporting people with dementia
- resources for supporting carers
- learning resources
- national strategies, standards and guidelines
- details of agencies and networks
- information specific to different care settings
- resources you can use to discover more

Next steps

We are currently collating examples of best practice and gathering the evidence so that others can learn from successes and find out how people have delivered and made positive changes to care.

We also plan to develop further resources and regional development programmes to support implementation of the commitment and increased understanding of integrated models of care for people living with dementia and their carers.

For further information please contact Rachel Thompson:
rachel.thompson@rcn.org.uk

Royal College of Physicians

Second Quarterly Progress report

- We have launched a project on medication in care homes , with RCGP, RCPsych and BGS.
- We have met with National Clinical Director for dementia.
- We have commissioned article for our College Journal (Clinical Medicine) on dementia.
- We have asked the examination department to look at including more questions on dementia in the MRCP examination.
- We are partners with RCN on Improving quality of care for people with dementia who are in a general hospital.
- We are working on Quality Mark for care in wards who deal with older people.

Third Quarterly Progress report

- The Royal College of Physicians has nothing to report for the past quarter.

Royal College of Psychiatrists

Please note that here we set out the organisation's plans to deliver better outcomes for people with dementia and their carers between October 2010 and 2014, and below each bullet point what progress has been made in the first quarter (October 2010 to February 2011)

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.

Progress: Members are encouraged to highlight and promote good service delivery and this discussed in the Executive committee and consumer forum Working Group set up of Old Age Faculty Executive Members Poster organised for residential meeting in March to encourage reporting of examples of good service delivery.

- Continue to work on the reduction of age discrimination which is particularly marked in the field of mental health.

Progress: Contribution to policy making through meetings of the Executive Council of the Royal College of Psychiatrists.

- 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.

Progress: Contact made with Directors of DeNDRoN, Scottish Dementia Clinical Research Network and equivalent networks in Wales and Northern Ireland.

- 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

Progress: Linked to Bullet 1 we are attempting to identify areas of new practice. This is achieved by the Faculty and by the College Divisions throughout England (ongoing)

- 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.

Progress: Meeting with Chief Executive of Alzheimer Society and Alzheimer Scotland. Meeting with Alistair Burns, National Clinical Director

- 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.

Progress: Nil to report.

- To improve quality standards of Memory clinics through national accreditation service and dementia wards through AIMS accreditation service.

Progress: Meeting on the 16 July to discuss UK wide remit of this group. A training curriculum in Old age psychiatry was approved by PMETB and Consumer forum has agreed to participate and offer help in the training of Psychiatric trainees

MSNAP Report received on the 16 February. A National Dementia audit is planned in General Hospitals by RCPsych to identify deficiencies in current service and promote good practice. Pilot is completed and full report is expected in Summer 2011

First Quarterly Progress Report 2012

- RCP gave evidence to the dignity in care commission Age UK, NHS Confed, IGA.
- Dr Linda Patterson, Clinical Vice President, attended press launch of CARE campaign by Patients Association.
- On going meetings with RCN and other partners on nurse staffing levels on older peoples wards.
- Ongoing work with RCpsych on piloting a Quality mark for wards caring for older people. We have 6 pilot sites.
- Tools for improving medication in care homes launched in November and being trialled. This project led by RCP, RCPsych and RCGP With 11 other partners. Paul Bastow, Minister of Health and David Behan Director General of Social Care attended the launch.

Saga Homecare

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

- Building on the reablement work already being undertaken, we intend to work with partners to develop and extend the services we provide to include people with more severe dementia. Research has demonstrated people with dementia are often excluded from such services because of poor outcomes. It is our intention to identify innovative solutions, working across health and social care to achieve positive outcomes for individuals.
- To support this work stream we will map our dementia training provision, identifying service hotspots and will invest by either self funding or by securing funding and will develop additional training modules to meet the range of needs for people with dementia.
- The promotion of dignity is one of the underpinning values of Saga Homecare. We plan, through a programme based on robust training and supervision, to develop both a dignity champion and branch based dementia recognition programme that will be rolled out across the business.
- Saga is a recognised brand providing a range of services and products predominantly aimed at the over 50s. Saga Homecare will work with colleagues in the wider organisation and in partnership with the Alzheimer's Society to highlight and raise awareness of dementia and associated issues in the public and political arena.

First Quarterly Progress report 2012

Saga Homecare have nothing to report this quarter.

Shared Lives Plus

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

- We will pursue funding for a major project to move Shared Lives from being a well-developed option in only some areas to being a mainstream part of the social care offer in most areas of England.
- We will work with research partners to find out what works for older people using Shared Lives and how to better tailor Shared Lives to their needs.
- We will support the dissemination of learning from the national dementia and Shared Lives project, hosted by SWAPS Shared Lives service.
- We will raise awareness of promising practice amongst our members, spreading learning, and help members working with people with dementia to form a community of practice.
- We will raise awareness of our members' work with people with dementia and their families.
- We will seek opportunities to work with user-led organisations to develop the voice of people with dementia and their families within our members' services and our own work.
- We will feed learning and ch1. 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?

First Quarterly Progress report 2012

Shared Lives Plus has just joined the Alliance so has nothing further to report for the past quarter

Skills for Care

Please note that here we set out the organisation's plans to deliver better outcomes for people with dementia and their carers between October 2010 and 2014, and below each bullet point what progress has been made in the first quarter (October 2010 to February 2011)

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 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)

Progress: All units have been completed and are part of the qualifications and credit framework

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 Qualifications and Credit Framework. (QCF).

Progress: Completed

- Skills for Care, jointly with Skills for Health, have developed a range of units on the Qualifications and Credit Framework that support workforce development on dementia specifically.

Progress: Completed

- 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

Progress: Ongoing

- 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)

Progress: Skills for Care and Skills for Health are also developing common core principles to support the dementia workforce across social care and health.

- 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). 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.

Progress: Completed

- 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.

Progress: Ongoing

- 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.

Progress: Ongoing work

First Quarterly Progress report 2012

Carers Matter - Everybody's Business is now complete and a link to the resources can be found here: <http://www.skillsforcare.org.uk/carers/>
The common core principles for supporting people with dementia have been completed and are available here:

http://www.skillsforcare.org.uk/developing_skills/dementia/supporting_people_with_dementia.aspx

Skills for Health

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.

First Quarterly Progress report 2012

Skills for Health have nothing to report for the past quarter.

Social Care Institute for Excellence

Please note that here we set out the organisation's plans to deliver better outcomes for people with dementia and their carers between October 2010 and 2014, and below each bullet point what progress has been made in the first quarter (October 2010 to February 2011)

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

Progress: New content added to Gateway includes features on Being withdrawn and Activity in the later stages of dementia; case studies on Food choices, Fronto-temporal dementia, Team work and leadership, and Responding to feelings unlocks solutions. Comms plan for further dissemination in development; business case developed to highlight expansion possibilities.

- Produce and promote three new Social Care TV films on dementia and disseminate to key audiences by March 2011

Progress: 3 SCTV films made and rough cuts viewed; final versions due in March; content covers end of life care, young onset dementia and participation in service development.

- 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

Progress: At a Glance briefing on personalisation and mental capacity completed and launched; available on SCIE's website at <http://www.scie.org.uk/publications/ataglance/ataglance33.asp>

- 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

Progress: A survey of what Local Authorities are doing to prevent abuse has been completed and the messages from this work will be published at the end of March.

- 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

Progress: The first draft of this guidance is currently being peer reviewed and should be ready for publication in March.

- Produce a research briefing on dementia in BME older people in the UK by December 2010

Progress: Research briefing on BME older people and dementia completed; awaiting launch date

- 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

Progress: Early intervention toolkit – Windows of Opportunity – completed and work undertaken to create interactive content. Currently being built by web team; ready for launch mid-March.

- 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

Progress: This will be one of our priorities for 2011-12

- 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

Progress: Guides on Access to the Court of Protection and The IMCA role in the Deprivation of Liberty Safeguards completed and due for launch in March. 4 training films also complete; to be launched end of March.

- 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.

Progress: Planning stages of project started; scoping work beginning early March; project aims to address the participation of older people with high support needs in SCIE and more broadly in health and social care.

First Quarterly Progress report 2012

Progress made against stated commitments during the period October-December 2011:

1. Develop and promote the Dementia Gateway to new and existing audiences, including the health care workforce

Progress:

- Work to restructure and redesign the Gateway progressed (for completion summer 2012)
- Update of resource section undertaken and new resources identified for inclusion
- Review of Gateway from a home care perspective completed
- New section 'Working in partnership with carers' completed in draft form
- New sections 'Early signs of dementia and getting a diagnosis' and 'Care and support following diagnosis' commissioned
- New section 'Sensory loss and dementia' in development – partnership approach with RNIB, SENSE, Royal Association for Deaf People, and Thomas Pocklington Trust taken to develop this content
- Project to learn more about using the Gateway to improve care home practice in development with Sussex Care Partnership Trust

2. To maximise choice and control for people with dementia and their carers, SCIE continues to develop products on personalisation.

Progress: Update of Research Briefing 20 **The implementation of individual budget schemes in adult social care** underway and will include specific search for evidence of how personal budgets are working for people with dementia (draft due June 2012); SCTV programme on risk enablement in development; update to personalisation e-learning programme planned and will include new modules on risk enablement and mental capacity to help address difficulties of personal budget uptake for people with dementia.

3. Safeguarding projects, including capturing service user views

Progress: SCIE report **User involvement in adult safeguarding** published September 2011 and SCIE report **Safeguarding adults at risk of harm: A legal guide for practitioners** published December 2011.

4. 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

Progress: project amended to better meet needs of sector, and has resulted in 2 pieces of work to be published February 2012. **Commissioning care homes for quality and safety** provides a framework for commissioners to use to check all safeguarding issues when commissioning care homes and **Common safeguarding challenges** provides commissioners and providers with information about the issues that most often result in safeguarding referrals from care homes.

5. Support the workforce to understand and implement the Mental Capacity Act, and support the quality of the Independent Mental Capacity Advocate (IMCA) service.

Progress:

- Set of MCA training materials aimed at care providers completed January 2012: these range from induction/introduction to the MCA to training for managers and specific training on the Deprivation of Liberty Safeguards. These materials introduced to SCIE Associates, who will be available to deliver the training, in January 2012
- Further training events provided to providers by SCIE MCA Implementation Managers in different parts of the country
- Presentations and workshops by Implementation Managers at provider trade association annual conferences
- On-going work to develop a guide to MCA compliance in care plans, for completion April 2012

6. Produce a research briefing on end of life care and dementia in residential care settings

Progress: draft briefing **End of life care for people with dementia living in care homes** completed; due for launch March 2012; At a Glance summary will also be available

7. Develop a new programme of work on integration, including developing an At a Glance about social care for GPs and research briefings on **Joint and integrated working** and **Promoting wellbeing in later life**. Both briefings are likely to have relevance for the care and support of people with dementia.

Progress: AAG on **Social care and clinical commissioning for people with long term conditions** has been launched; Research briefings **Joint and integrated working** and **Staying well in later life**, together with associated Social Care TV programmes and At A Glance summaries underway and due for launch May 2012.

8. Identify and explore the factors that influence the participation of older people with high support needs, including those with dementia, in service development and delivery

Progress: internal report completed which provides a summary of messages from the literature on the participation of older people with high support needs; peer review of report very positive and it will now be published externally; further possible work in this area being explored.

9. Work closely with NICE to pilot the development of a social care quality standards, focussed on dementia care

Progress: work so far has included commenting on and contributing to the draft scope, attending initial stakeholder workshops and the recruitment of TEG members. With the first TEG meeting scheduled for 30/31st January, we will have significant continued involvement both via observer roles for the TEG and an expert adviser role within the project group.

Stroke Association

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 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.

First Quarterly Progress report 2012

The Stroke Association has nothing to report for the past quarter.

The Journal of Dementia Care

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

- JDC has plans to maintain its role as the leading dementia - focused publication in the UK bringing a carefully considered mix of news, features, research evaluation and comment both nationally and internationally. In particular it is considering extending electronic content on its website www.careinfo.org.
- JDC plans to extend its range of dementia events and publications Partnership : JDC plans to develop closer relationships with dementia organisations

First Quarterly Progress report 2012

The Journal of Dementia Care has just joined the Alliance so has nothing further to report for the past quarter

Thomas Pocklington Trust

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.

First Quarterly Progress report 2012

Thomas Pocklington Trust has nothing to report for the past quarter.

University of Stirling: Dementia Services Development Centre

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 on line library

First Quarterly Progress report 2012

In the past quarter we have continued to seek funding for projects which allow us to offer free or reduced cost publications, places on training and degree courses, and information sessions. As a result, we can get our message out to as wide an audience as possible. Publications like 10 Helpful Hints for Dementia Design at Home and 10 Helpful Hints for Carers, which are full of sensible advice, are given to family carers at sessions funded by Comic Relief, which we are running in Scotland initially, hoping to attract funding to extend it more widely.

The Best Practice in Dementia Care training programme for healthcare support workers in hospitals and care homes has been extended with the launch of the programme for domiciliary care workers, and this is being rolled out throughout the UK.

Improving design of care environments is always high on our agenda. We continue to offer paid consultancy but also free information and opportunities to visit our Design & Technology Demonstration suite. Access is being further extended through the development of a Virtual Care Home, due to be launched on 20 March on the DSDC website, which will demonstrate principles of good design by means of clickable room settings. Anyone, anywhere will be able to visit (virtually) and get ideas for improving environments for care.

In terms of staffing, we have appointed a new post of Training Officer, and we are currently recruiting a Chair in Dementia Research.

Internationally, we are working with Hammond Care in Sydney, Australia on a number of publication projects, and planning an international conference to be held in June 2012

WRVS

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

- WRVS plan to reach out to existing and new partners to share the proven impact of the services that WRVS provide, we intend to stimulate both potential referrals of older people including those living with dementia's and identify funding to enable WRVS to help and support more people. Our growth strategy is ambitious and when in operation it will enable WRVS to share best practise from one community to another.
- WRVS are actively attracting and recruiting new types of volunteers that will enable us to deliver our vision for WRVS services, we are developing new opportunities, streamlining our processes and increasing our visibility both nationally and locally.
- WRVS are also focusing on being very clear about the social impact of what we do and how this can support those living with Dementia's, we are joining up our services and providing an integrated offer to those living at home or in clinical environments. Older people will be in the driving seat in the development of individual care packages which will be outcomes focused and relevant to the individual.

First Quarterly Progress report 2012

WRVS is in the process of appointing a design consultancy to lead it in our aim of making all our hospital based cafes environments dementia centred.

WRVS is finalizing its on-line dementia training modules to enable it to achieve its aim of making all WRVS Staff and Volunteers dementia aware.

YoungDementia UK

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

- Continue developing and improving the individual support for younger people with dementia – create opportunities to enrich life, connect to the local community and fulfil everyday activities and special wishes too
- Further develop early stage support for family members and for younger people immediately after diagnosis to help them emotionally, practically and with information.
- Improve advanced stage, end of life and bereavement support for family members.
- Use YDUK website to develop young onset dementia network and share experience with other organisations and professionals
- Develop YDUK website to link younger people and families in the UK
- Develop specialist small-scale accommodation for short breaks and long term for people with young onset dementia

First Quarterly Progress report 2012

YoungDementia UK has just joined the Alliance so has nothing further to report for the past quarter