

Delivering the National Dementia Declaration for England

Second Quarterly Progress Report May 2012

DAA Dementia
Action Alliance
www.dementiaaction.org.uk

We have received a Quarterly Update from:

360 Forward
Age Related Diseases and Health Trust (ART)
Age UK
Alzheimer's Research UK
Alzheimer's Society
Anchor
Association for Dementia Studies, University of Worcester
Association of Directors of Adult Social Services
Bradford Dementia Group
British Association for Counselling and Psychotherapy
British Geriatrics Society
British Psychological Society
Bupa Care Services
Care UK
Carers Trust
College of Occupational Therapists
Dementia Advocacy Network
Dementia Services Development Centre
Department of Health
Design Council
ECCA
Four Seasons
HDRC/ Housing 21
Jewish Care
Joseph Rowntree Foundation
Ladder to the Moon
Lewy Body Society and Parkinson's UK
Life Story Network
Lost chord
Mental Health Foundation
MHA Care Group
My Life Software
NAPA
National Care Forum
National Council for Palliative Care
National Institute for Health and Clinical Excellence
National Skills Academy for Social Care
ndti
NHS Confederation
NHS Institute for Innovation and Improvement
Orders of St John Care Trust
Royal College of General Practitioners
Royal College of Nursing
Royal College of Physicians
Shared Lives Plus
Skills for care
Social Care Institute for Excellence
Social Care Workforce Research Unit, King's College London

The Good Care Group
Thomas Pocklington Trust
Vitalise

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 800,000 people with dementia in the UK and this number is set to grow to over one million people by 2025. The financial cost of dementia in the UK is £23 billion each year and growing. 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 national organisations signed up to the National Dementia Declaration have formed the Dementia Action Alliance. This has now grown to 113 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.

Alliance members submit quarterly progress reports on their plans, which are set out in this document. The updates below cover the period from February to May 2012.

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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Action:

Developed Work-based Learning in Health and Social Care Pathways to Person Centred Care supporting, embedding and sustaining the delivery of the Declaration outcomes

360 Forward courses have been designed to help all staff and managers at all levels of organisation acquire the unique blend of knowledge, skills and behaviours that enable people using services to experience good care and support, family and friends to have confidence in the quality of care, and staff to find the work fulfilling, (Parts 1, 2, and 3 of the 360 Standard Framework).

Key areas of learning for achieving person centred care based on positive relationships are woven into all our course topics that support developing and sustaining relationship based cultures that deliver person centred outcomes. Adult learning and blended learning methods include work based projects and action research which has the added value of achieving planned organisational and practice development objectives.

Progress:

- **360 Forward Primer Courses now available** start the process of acquiring the knowledge, skills and behaviours necessary for achieving this primary goal. Primer courses are run as half day workshops, which can be followed up with an *on the job learning* project and review
- **360 Forward Intermediate Courses** advance the depth and scope of the knowledge, skills and behaviours necessary for achieving person centred outcomes from the separate but related perspectives of the person, their families and staff. Some are now available and will be advertised on the website in June

Action:

- **Activity at the Heart of Care**, as resource to support 'how to do' outcomes for excellence in providing a meaningful day (Resident Std 2) including steps how to provide occupational activities to people at different stages of dementia

Progress ; To be launched in June as PDF and later as EBook

Action

- **Anyone for Tea?** a unique and practical learning resource to help health and social care staff who come from other cultures to understand shared history, customs and traditions of the English. It includes Intergenerational comparisons with ideas to support therapeutic conversations with people with dementia to tap into long term memory

Progress : to launch in June as PDF and develop into an EBook

360 PQ interview methods developed with Talking Mats to involve people with dementia in continuous quality improvement:

Progress: first course running in May in Hampshire

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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Over the past quarter ART has continued to lead the DAA Campaign on Timely Diagnosis, which aims to increase the proportion of people with dementia receiving a timely diagnosis and ensure that appropriate care pathways are in place post-diagnosis. We have now established an advisory group including members from the Department of Health, NHS Institute, SCI, BUPA, British Geriatrics Society and the All-Party Parliamentary Group on Dementia. In the first phase of the campaign, we conducted a scoping exercise to determine which organisations are actively working to promote timely diagnosis, and where the obstacles lie. We are now moving into a second phase, which will concentrate on actions to remove those obstacles, working with key influencers within the DAA. ART is also co-ordinating the DAA's response to the forthcoming APPG report on early diagnosis.

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:

Dignity in Care

A partnership on dignity in care between Age UK, the NHS Confederation and the Local Government Group established an independent Commission on improving dignity in care for older people in hospitals and care homes. At the end of February 2012 the Commission on Dignity in Care published its draft report and recommendations with 10 key recommendations each for hospitals and care homes.

The report highlights the number of people with dementia in both settings, sets out some of the changes needed to practice, and makes specific recommendations for action.

Following a month of consultation on the draft report, the Commission is now considering the feedback received and is developing its final report which will be accompanied by an action plan.

Further information is available at: www.nhsconfed.org/dignity

My Home Life

Sponsored by Age UK, City University, the Joseph Rowntree Foundation, and Dementia UK, *My Home Life* (MHL) is a collaborative partnership aimed at improving the quality of life of those who are living, dying, visiting and working in care homes for older people.

My Home Life has completed a series of films commissioned by the Department of Health and produced in conjunction with Let's Respect and Dementia UK. The films look at the challenges of dementia and other mental health issues in residential care. They are available to view at: <http://myhomelife.org.uk/resources/dementia/>

Training

Age UK Training is this year focusing on offering training in dementia as a core product available to health and social care providers. More information is available in Age UK Training's course brochure.

Research

Age UK continues to fund a major research project on cognitive ageing: the Disconnected Mind project at the University of Edinburgh.

Under our Research into Ageing Fund Programme, we continue to fund a variety of research projects on dementia and cognitive impairment in later life at a range of UK academic institutions. As at April 2012 we are supporting four projects at King's College London, Newcastle University, University College London, and the University of Edinburgh.

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 2011, the APPG on Dementia launched an inquiry into how to improve dementia diagnosis rates in the UK. The inquiry saw over 1,000 people, including people with dementia, GPs, Royal Colleges and carers, respond via a survey. Two oral evidence sessions were also held at the Houses of Parliament, where parliamentarians listened to people present their views on diagnosis - including people with dementia, health and social care practitioners, and speakers from the Scottish Government and College of Social Work. The report will be officially launched in July 2012.

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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- In March 2012, Alzheimer's Research UK welcomed the Prime Minister's 'Dementia Challenge'. This included an important section on 'Better research' which pledged to double dementia research funding by 2015 and a number of key commitments. The 'Better Research Champion Group' will be led by the existing Ministerial Advisory Group on Dementia Research (MAGDR) of which Alzheimer's Research UK is a member. Prior to the announcement, Alzheimer's Research UK worked with the Department of Health and Number 10 to discuss ideas for prioritising dementia research.
- Over 250 dementia scientists from around the world gathered in Birmingham on 27 – 28 March for our 13th Annual Network Conference to share the latest evidence on a wide range of research topics. The event included talks from leading UK based scientists on midlife risk reduction and the importance of early life cognition in understanding cognitive ageing.

- So far in 2012, we have awarded almost £1m of new grants. At our Scientific Advisory Board meeting in January, we awarded 14 new grants, including six PhD Scholarships and five Pilot Projects Grants. These new projects cover a wide range of important topics including MRI imaging of Alzheimer's, understanding the role of the immune system in Alzheimer's, investigating how amyloid may contribute to Parkinson's dementia and unravelling the genetics of frontotemporal dementia.
- Alzheimer's Research UK continues to deliver on actions arising from the MAGDR route map. Working with the Alzheimer's Society and DENDRON, we are currently working towards the soft launch of a new dementia research portal this summer.

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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- On March 26th, Alzheimer's Society hosted the Dementia 2012 conference in London and launched our *Dementia 2012: A national challenge report*. The report describes how all people are living with dementia in 2012 in England, Wales and Northern Ireland.
- The Prime Minister, speaking at the Alzheimer's Society's conference in March, launched his challenge on dementia - delivering major improvements in dementia care and research by 2015. There are three key areas of focus: improvements in health and care, creating dementia friendly communities that understand how to help, and better research.
- As part of the Prime Minister's Challenge Jeremy Hughes, Chief Executive of Alzheimer's Society, and broadcaster, Angela Rippon OBE, are the Co-Chairs of the Dementia Friendly Communities Champion Group. The Champion Group will report to the Prime Minister in September outlining what action needs to be taken to create dementia friendly communities.
- The Prime Minister visited Alzheimer's Society to listen to the views and opinions of the Champion Group about what action needs to be taken by organisations to become more dementia friendly.
- The Champion Group for Dementia Friendly Communities has launched a public engagement exercise seeking views of how to create dementia friendly communities. The consultation questions can be accessed at:
<http://dementiachallenge.dh.gov.uk/2012/05/28/dementiafriendlyquestions/>
- We have attended a number of meetings with Department of Health officials to discuss social care reforms in England, ahead of the publication of the White Paper.
- The theme of this year's Alzheimer's Society Dementia Awareness Week (May 20 – 26) was "remember the person". During the week, we launched the five things you should know about dementia.
- We met with the Department of Work and Pensions Partnerships team and explored ways of linking their work to the activities of the Alzheimer's Society.
- The policy team are working on a project to look at the quality of care for people with dementia who live in care homes.

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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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 colleague development:

- 269 employees have completed the dementia awareness session Introduction to Dementia Care.
- 36 employees have attended and completed the intermediate session, Improving Dementia Care.
- 290 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.

275 employees attended a wide range of dementia knowledge development sessions, many are bespoke to meet individual service need including, customers life stories, rarer causes of dementia, understanding communication as behaviour, night time activity, depression, later stages of dementia, enhanced dining, activity and meaningful occupation, leadership and promoting best practice dementia care 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 16 sessions around the country 46 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 living with dementia.

How to develop individual 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.

Individuals linking to Dignity in Care network, Skills for Care and community older peoples groups.

The volunteer initiative continues to make significant progress in the Yorkshire. We currently have 147 volunteers across 8 sites all matched with individual customers to meet specific individuals specific interests and hobbies. A further 3 Care Homes have now joined the initiative with 8 offers outstanding and further interviews arranged for the month of May. The roll out

programme is picking up pace with a further 2 Care Homes joining in May, this will make a total of 14 Care Homes benefitting from the initiative.

A further 85 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 those wanting to gain work experience.

We have 56 volunteers who have completed their 6 month volunteering commitment. In addition 12 of these people have now applied for a permanent care post and have been successfully recruited. In total we have benefitted from 203 volunteers and have a further 85 waiting to join us.

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 18 months in care homes we have more than doubled the number that have commenced, this positive trend has continued over the last 3 months with many care homes having 100% of customers with a living story.

Supporting housing colleagues to find positive solutions for those customers living with dementia and those recently diagnosed.

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 of antipsychotic medication.

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 reviews has increased.

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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We have continued to promote and distribute copies of our “Stand by Me” DVD assisted training resource on good communication between health care staff and people living with dementia and their families. Funded by Herefordshire and Worcestershire Workforce Deanery this has brought together a wide range of front-line staff, young film makers, people with dementia and their families and our academic staff.

<http://ihsc.worc.ac.uk/dementia/standby.html>

We have also completed a web-based resource toolkit designed for care homes managers wanting to improve person centred dementia care based on the VIPS framework. The website is called Care fit for VIPS and was produced in partnership with Equip4change and Crystal Presentations. It was funded by West Midlands SHA as part of their strategy to decrease anti-psychotic prescribing in care homes for people with dementia.

<http://www.carefitforvips.co.uk>

We are working with Uniting Carers in providing family carers as tutors on our courses and are developing ways of involving people living with dementia as course tutors. Our steering group includes members who have dementia and those with family caring experience.

We are working in partnership with a number of national care-home providers and NHS Trusts, a city council and a county council, large acute hospital trusts, housing with care providers and hospices in working towards service excellence.

We successfully tendered for the lead for a EU programme of work on Early Diagnosis and Interventions through the ALCOVE programme which we commenced in January 2012

<http://ihsc.worc.ac.uk/dementia/alcove.html>

Jenny La Fontaine (Senior Lecturer) was awarded a prestigious Florence Nightingale Foundation Research Scholarship for Nurses and Midwives to assist in undertaking PhD research at Birmingham University into the impact of fronto-temporal dementia.

We have been active in undertaking commissioned research and development including the development of the care fit for VIPS website.

<http://ihsc.worc.ac.uk/dementia/vips.html>

We have been engaged in research and development on an NHS West Midlands programme with the Royal Wolverhampton Hospitals NHS Trust in developing services of excellence in the acute hospital.

<http://ihsc.worc.ac.uk/dementia/excellent.html>

We continue to deliver an extensive programme of bespoke education courses on early interventions, care homes, acute hospital care, specialist housing and end of life care. We have also delivered professional accredited action learning sets (varying duration between 5-12 days) including

- leadership & management in dementia care
- specialist/champion/locksmith courses
- specialist mental health courses
- dementia course for commissioners
- specialist dementia course in acute hospital care.

During this period we have delivered a range of courses to care home and local authority staff including Person-Centred Dementia Care, Care Home Dementia Specialists and Health and Social Care Leadership.

All our courses have evaluated extremely well with course participants often commenting that this has been the best dementia education they have ever received and at follow-up 6-months later reporting real changes in practice in their care and support of people living with dementia and their families.

<http://ihsc.worc.ac.uk/dementia/courses.html>

Continuing expert consultancy on the dementia friendly acute hospital and development of care bundles for people with dementia in acute hospitals.

Successful tender for development of person centred care home tool kit

Continuing the development of a network of trainers and educators in dementia care in West Midlands.

Member of the national Work-force advisory group.

Contributions continue to the SCIE Dementia Gateway

Over the past year collectively we have provided 12 national and international conference presentations and have taken part in external examining, reviewed for peer review journals and research councils and contributed on editorial boards for learned journals.

Seminars delivered on person centred dementia care; Enriched opportunities, leadership, dementia fundamentals; person centred care for Health Care Support workers.

Kate Read, senior lecturer at ADS, has continued to lead on Dementia UK activity within the West Midlands and has supported a growing number of Admiral Nurses within the region and beyond. We have supported Dementia UK West Midlands networks on Memory Clinics and Liaison Psychiatry. We have also been successful in gaining funding with Dementia UK to evaluate their 'Carer Educators' programme.

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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ADASS has made progress against its commitments in the following areas:

- made a written submission to the All Party Parliamentary Group on early diagnosis
- participated in a high level breakfast meeting on early diagnosis
- continues to be represented on the NICE Topic Expert Group on dementia and participated in its second meeting on May 14 and 15
- its President is one of the two champions for the Health and Social Care aspect of the Prime Minister's Challenge
- is joining the housing and dementia working group
- attended the workshop on Call for Action in acute hospitals on May 24 and will ensure that there is social care input to the task group taking this forward

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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We are creating a section on our web pages where people with dementia and their families can see the various ways they can engage with us.

EDUCATION

We continue to work in partnership with people with dementia and their family carers in the design, delivery and assessment of our accredited distance learning modules for our BSc and MSc dementia studies.

Service users with dementia contribute to teaching on the MSc Dementia Studies (Training pathway). Their contribution has been videoed and will be used to demonstrate innovative teaching methods and presented at the UK Journal of Dementia Care Congress.

TRAINING

In partnership with Bupa, we are developing a training programme for families and supporters of people living with dementia and supporting them before, during and after their loved one has moved into a care home. Our approach involves running focus group sessions with families to understand their needs in relation to content and format of the training programme.

RESEARCH

Our research continues to be informed by the concerns of people with dementia. Our NIHR research projects are conducted in partnership with people with dementia and their family carers. For example, members of a local day centre for people with dementia have been recruited to the advisory group for our NIHR funded project on Participatory Video with people who have dementia.

CONSULTANCY IN PRACTICE DEVELOPMENT

We are partnering with people with dementia and their families in a major care home culture change process.

We serve on the National Dementia Strategy Workforce Advisory Group.

We maintain an ongoing supportive relationship with Cannon Care Homes, to develop a model of excellence in dementia care within the organisation. We have:

- facilitated sessions with all grades of staff within the three homes, to develop their ideas to assist people living there in leading fulfilling lives;
- supported the staff in developing plans to put these ideas into action;
- worked with key staff in the use of the Bradford Well Being Profile to inform person centred care planning, to improve well being and quality of life for people who live in Cannon Care Homes.

We are continuing to work with Rotherham Metropolitan Borough Council to develop the workforce across their residential and community based dementia services provision.

We are working with Kent County Council and Kent and Medway NHS Social Care Partnership Trust to support care homes in Kent to bring about improvements in wellbeing for people with dementia. The project will run over 12 months and will monitor changes brought about by multi layered training including Leadership in Person Centred Care and DCM.

We are currently working with Signature Senior Care to develop and embed a new system of person centred care planning that reflects contemporary person centred practice and facilitates individualised person centred interventions for residents that enhances wellbeing

Staff and students

We continue to hold a staff support group for University staff who are caring for people with dementia.

We have supported Occupational Therapy students in their learning associated with working with people with dementia.

In collaboration with the Alzheimer's Society, we held a dementia awareness event at the University of Bradford during dementia awareness week.

A paper which describes using musical choice to explore life histories of people with dementia has been accepted for publication by the Journal of Applied Arts and Health. The paper is based on a coursework project carried out by BSc (Hons) Dementia Studies students.

One of our BSc students wrote up the Bay Tree Voices film project, which involved people with dementia in producing film clips to be used as teaching resources. The student's report on the project has now been featured on the University of Bradford's Community Engagement web page.

We are leading an NIHR Programme Development Grant on ***Improving health care in care homes*** collaborating with colleagues in a range of sectors throughout the UK as well as academic colleagues in the Netherlands and the US. To complement this work, the University has created a PhD studentship to explore the area of improving health care in care homes. We have appointed to this post.

We are leading on an NIHR Social Care project exploring the use of ***participatory video with people with dementia in care homes***.

We are continuing to work with two local NHS Acute Hospital Trusts to test the ***effectiveness of evidence-based training materials and models of learning on staff knowledge, skills and attitudes towards people with dementia***. We are also measuring the effectiveness of this training on the experience of care for people with dementia in acute hospital settings.

We are evaluating the ***Arts based Community Programme*** implemented by Opera North and Bradford District Care Trust. The eight week programme

aimed at involving people with dementia and their carers living in the community includes singing and storytelling. We are evaluating the impact of the programme on the engagement and well-being of people with dementia and their carers.

We serve on the Project Board for Enabling Research in Care Homes (ENRICH) and have assisted with the development of the web-based toolkit for conducting research in care homes.

We have engaged in a round table discussion hosted by the Joseph Rowntree Foundation on dementia in Bradford.

WEB PAGES

We have invested in ensuring our web pages provide easy access to our research-informed training, education and consultancy.

TRAINING

We are continuing to work with several organisations to develop an adapted version of Dementia Care Mapping for use in the person's own home: Dementia Care Mapping for Supported Living (DCM-SL). The tool can be used in this context to develop staff knowledge and skills in person centred care. We have delivered our first course on DCM-SL for organisations. We will continue to support these course participants to embed this approach in care practice.

We are developing Apprentice Dementia Care Mapping Trainers both in the UK and internationally to achieve approved Dementia Care Mapping Trainer status. We are also supporting our international Partners in Dementia Care Mapping to update their skills to Advanced Dementia Care Mapping Trainer status.

We have been commissioned by Doncaster Council to deliver Learning to Use Dementia Care Mapping within their organisation.

We have delivered bespoke training on Conducting qualitative research with people with dementia to colleagues at the University of Leeds and Oxford Brookes. The aim of the training was to support researchers' understanding of how to engage and empower people with dementia in research.

In partnership with the University of Bradford's Division of Service Development and Improvement we have delivered Developing Leadership in Person Centred Care. Course participants are supported to develop a comprehensive action plan to deliver improvements in the quality of person centred care in their own workplace, by reflecting on individual, team and organisational leadership styles.

We are working in partnership with Methodist Homes to develop and deliver staff training for their workforce. The training approach includes the development of in-house peer facilitators and a bespoke training programme.

We have developed a new, flexible training programme for acute hospital staff on caring for people with dementia. Following feedback and evaluation, we will be providing this training nationally in the coming months.

We have delivered two days on person-centred dementia care for staff on the Management pathway of Ideal Care Homes, and have been commissioned to deliver two more days in July.

ACCREDITED EDUCATION

The University has validated the first programme nationally for Primary Care Practitioners with a Special Interest in Dementia. The Postgraduate Certificate delivered in conjunction with East Sussex Joint Commissioning Team will provide primary care practitioners (GPs and nurses) with cutting edge, evidence-based, specialist knowledge on assessment, diagnosis, prescribing and psychosocial support for people with dementia. This will allow for the majority of diagnostic services to be delivered by GPs in the community, with more specialist diagnostic services being offered in secondary care memory services. This Postgraduate Certificate is available to organisations who wish to improve the primary care response to dementia.

We continue working on our long term project with Nightingale - Hammerson in London to bring about sustainable culture change across the Home. We are training and mentoring Person Centred Care Champions to support their peers in understanding and supporting the needs of people living with dementia. Champions are drawn from across the staffing team including deputy managers and domestic staff. Additional ongoing changes to the care culture include:

- review and restructuring of Home routines;
- restructuring supervision systems;
- removal of uniforms;
- medication dispensed from individual bedrooms;
- enhancing of mealtime experiences;
- increased activity and meaningful occupation;
- creation and empowerment of resident forums;
- key worker systems;
- enriched care planning;
- embedding DCM as part of whole system quality improvement cycles;
- mentoring managers and senior care staff on leadership skills.

We have started a project with Northumbria Healthcare NHS Trust working across two clinical settings to develop person-centred care practice. We are providing training in person-centred dementia care, Dementia Care Mapping and Leadership in person Centred Care along with support to transfer knowledge and skills into practice. We are utilising change methodology to improve the experience of care for people with dementia with a focus on mealtimes, activities and life story work.

Research development

We continue to host the cross-School dementia research development forum. In collaboration with colleagues in University's School of Computing, Informatics and Media, we have been successful in getting to the second round of an EPSRC wild call. Our proposal centers on the development of a memory bank for people with dementia.

We are currently preparing a Programme Grant submission in the area of Improving health care in care homes.

Research dissemination

We have developed our web pages to improve accessibility of our ongoing and completed research.

Findings from our evaluation of the Yorkshire Film Archive initiative, Memory Bank, have been covered by the press.

Findings from the ESRC-funded study on decision making and dementia are being presented as part of the University's disseminating research initiative.

We have provided information on fees and sources of support for fees on our course marketing material – both paper based and web.

Public lectures

We have held a public lecture at the University on understanding dementia, attended by over 100 participants including members of the community, voluntary, statutory and private care sectors, students and staff.

Next lectures include:

Prof Ouslander (from Atlantic Florida University) on June 25 ***Improving health care in care homes.***

In collaboration with Alzheimer's Research UK, ***Finding out about dementia*** on June 18

Conference contributions include:

- With Leeds Mental Health Partnership NHS Trust we have disseminated findings of a project using DCM to develop care practice.
- We have presented at the Journal of Dementia Care Conference in April on the positive outcomes from changes to medication procedures in a care home project.
- We have presented and engaged in workshops at Oxleas NHS Foundation Trust supporting system transformation and person centred care.

Social networking

We continue to use Facebook and Twitter to promote discussion and debate on contemporary issues in dementia policy and practice.

Media

Our specialist expertise has been featured on a BBC Panorama programme on care for people with dementia in care homes.

Other

We have participated in the launch of Calderdale Council's scrutiny on dementia, Dementia, a Bold Approach.

We serve on the NIHR Dementia and Neurodegenerative Diseases Research Network Clinical Studies Group.

We serve on the Alzheimer's Society's Research Advisory Council Executive.

British Association for Counselling & Psychotherapy

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

BACP will commission research into the effectiveness of counselling for carers of people with dementia and the qualitative experiences of those carers:

- BACP has commissioned the University of Manchester to conduct a systematic review entitled, 'Counselling and psychotherapy for the carers of those with dementia: a systematic review of the research literature'. The team comprises Dr Ruth Elvish and Dr John Keady who will begin the project in early January 2011. The review aims to systematically review existing research and identify the effects of interventions and implications for policy and practice.
- The University of Manchester has also been commissioned to conduct a qualitative project entitled, 'Investigating dementia carers' experiences'. This project will investigate the experiences of those caring for a person with dementia, exploring their emotional and psychological needs. The focus of the study will be on the potential role counselling and psychotherapy can play in providing support for carers of those with dementia.

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The systematic review commissioned by BACP '*Psychological interventions for carers of people with dementia: a systematic review of quantitative and qualitative evidence*', by Ruth Elvish, Sammi-Jo Lever, Jodie Johnstone, Rosanne Cawley and John Keady (The University of Manchester), has now been published. Twenty studies were identified, doubling the number of studies that have been examined and synthesised into review literature since the review undertaken by Gallagher-Thompson and Coon (2007). Consistent with previous work (Gallagher-Thompson and Coon, 2007), three categories of psychological intervention were identified: i) psycho-educational skill-building; ii) psychotherapy-counselling; and iii) multicomponent. In addition, there were studies that the researchers grouped into a newly created fourth intervention category which was named iv) technology-based. Whilst cognitive-behavioural approaches were a significant influence within the psycho-educational skill-building and multicomponent categories, the model underpinning psychotherapy-counselling studies also focused on the marital unit and the marital relationship as targets for change.

The ten findings and recommendations are summarised as follows:

- Consistent with previous reviews on this topic area, the findings suggest that interventions underpinned by cognitive/cognitive-behavioural models can produce meaningful change.
- Multicomponent and technology-based interventions that use a combination of individual and group sessions are most effective.

- The qualifications of practitioners who delivered psychological interventions within this review are varied; standardisation of training/qualifications would be beneficial for clients and clinicians.
- Studies that explore and evaluate the impact that the mode of delivery has on process and outcome are called for, particularly in the use of technology.
- Further research is necessary that explores the processes of change within psychological interventions.
- An increase in the number of studies, possibly clustered around a programmatic multi-centre study measuring the impact of psychotherapy and counselling on carers of people with dementia, is required.
- The number of UK-based studies in this field should be increased, together with an examination of the cost-effectiveness of delivering various types of carer-focused interventions.
- There is a continuing need for public and social policy to focus on stigma and dementia within ethnic minority cultures, and particularly the impact of stigma on use and accessibility of services.
- In England, the commissioning strategy attached to the National Dementia Strategy should consider technologybased interventions as a support for carers of people with dementia.
- The updated findings for carer interventions from this review should be considered for inclusion in any revised national dementia guideline.

This review is available for free as an online pdf for BACP members and non-members alike. There are no hard copies of this review for purchase. For more information and to download the review, please visit <http://bacp.co.uk/research/publications/index.php>.

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*

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- 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: First 2 Clinical Forum Briefings on Meaningful Activity and Dementia, Delirium and Depression now available to members.

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: Ongoing study days and Masterclass being offered to members.

Action: Article in OT News explaining the Prime Minister's challenge on dementia and requesting occupational therapists consider the following: How are you improving the experience of people living with dementia – have you ideas to enhance their experience? There is an Innovation Challenge Prize of £1m NHS staff can win for innovative ideas for transforming dementia care.

In terms of creating dementia friendly communities - is your work environment dementia friendly? If working within a dementia service- how aware of your services is your local community? What steps can you take to improve on this? Finally, How can I / our service be involved in research? Within memory services: are people living with dementia and their carers being offered the opportunity to participate in research? This will become a requirement to achieve accreditation through the Memory Services National Accreditation Programme (MSNAP).

- Promoting the National Institute for Health and Clinical Excellence (NICE) Public Health Guidance 16.

Action: 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: Ongoing: 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: Ongoing; 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

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1. Membership of Royal College of Psychiatrists and Royal College of Physicians -Dementia Quality mark in Acute hospitals.
2. Membership of the National Dignity Council.
3. Membership of the National Council for Palliative Care Older People's group where they will be discussing the Prime Minister's Dementia Challenge and hopefully promoting the importance of end of life care in advanced dementia.

All groups emphasise the importance of quality care in Dementia.

British Psychological Society

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

The National Lead for Dementia (within the Faculty of Old Age Psychology) will lead a strategic work stream for the next two years to articulate and champion psychological approaches in dementia care. This will include the following:

- To build on existing dementia pathways to articulate the role of psychological interventions at all stages along the pathway (in line with the dementia strategies/plans of the four nations)
- To highlight effective alternatives to the use of antipsychotic medication in managing the behavioural symptoms of dementia
- To produce a national guideline on best practice in managing the behavioural symptoms of dementia, possibly as a transdiagnostic guideline (e.g. in conjunction with the Learning Disability specialty) and/or in conjunction with other organisations (e.g. Alzheimer's Society) and/or with other professional colleges (e.g. Royal College of Psychiatry)
- To approach the National Institute for Health and Clinical Excellence (NICE) to produce a clinical guideline for the management of behavioural symptoms in dementia
- To continue to work with other bodies to ensure high standards of practice in dementia care (e.g. the RCP Memory Services National Accreditation Programme, National Mental Health Development Unit)
- To deliver high quality, affordable training events to psychologists working with people with dementia, in collaboration with other partners where possible (e.g. Division of Neuropsychology, Royal College of Psychiatry)
- To support psychologists to train other professions in the effective management of challenging behaviour
- To support the development of 'intelligent targets' in dementia (led by Prof Robert Woods, University of Bangor)
- To continue to advise Clinical Psychology training courses on the core competencies required for working with older people
- To work with training courses to revise their curricula in light of the pathways development and national guideline for behavioural symptoms in dementia
- To work with the Care Quality Commission to develop quality and risk profiles for practitioner competencies for working with people with dementia
- To continue to develop the evidence base for effective psychological practice in the dementia pathway.

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- The National Conference of the Faculty of the Psychology of Older People (PSIGE), taking place in Bristol on 14/15 June 2012 will include half day workshops on psychological interventions dementia:
Professor Bob Woods and Dr Mike Bird, Dementia Services Development Unit, Bangor University:
Improving quality of life for individuals with dementia in the early stages
– adapting to need and demonstrating effectiveness
Meeting individual and complex needs of individuals in residential care
– supporting staff and using measurement scales
- A working group has completed a draft of a Briefing Paper outlining a stepped approach to psychosocial interventions in behaviours of stress and distress in dementia, and reviewing the evidence base. The paper is now in the review process and expected to be published in autumn 2012.
- The Division of Clinical Psychology has agreed to focus on the needs of older people, and particularly people with dementia, during a full day of its annual conference in Oxford in November 2012, facilitated by the dementia work stream group:
- Invited keynote speaker, Dr. Ian James, will speak about psychological well being in care homes and a panel of nationally recognized psychological experts are speaking on the current evidence base for psychological interventions in dementia.

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.

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A total of **204** Alzheimer's Society trained Dementia Champions set the cultural tone and shape practice on our registered dementia specialist unit. (as of May 2012)

More than **12,639** staff have now completed or are underway with The Essentials foundation training. **152** Person First Coaches have been trained (as of May 2012) to deliver the Excellence core modules of more advanced or specialist care skills and knowledge.

Following a successful pilot in 2011, this year we commenced a specialist care home refurbishment and development programme. This will deliver living environments that support abilities, provide a sense of home and community, and are meaningful for people living with dementia. As of end of April, 6 homes have dementia friendly refurbishments underway.

Action continues to be taken to reduce prescribing of antipsychotics underpinned by six-monthly audits. This information is being shared within the DAA/NHS Institute for Innovation and Improvement 'Leaders of Care Homes' commitment group. Our latest innovation is to pilot an anti-psychotic screen that establishes on admission to a care home whether a person is already prescribed an antipsychotic medicine which in turn triggers a review and on-going governance.

With our partners at Bradford University Dementia Research Group we are designing a family carers' education resource that will be delivered in Bupa's care homes by our Dementia Champions and Person First Coaches. It is for relatives who are negotiating the transitions to care that is now being provided for a loved one in a care home and for families who wish to learn more about dementia and wish to look to the future with knowledge.

In partnership with Carers UK Bupa provides an interactive website, Carewell. In February we ran a Q&A session for family carers, addressing everyday issues of health and personal care.

We contributed to the Prime Minister's Challenge on Dementia. Bupa participated in consultations and submitted "Our Compact with People Living with Dementia" as a template to illustrate how a provider of care homes could meet the needs of people living with dementia and their families.

We submitted written evidence to the APPG Inquiry into Barriers to Early Diagnosis.

We continue to present Dementia Seminars around the country for health and social care professionals, and have now started to run 'Friends and Families' public meetings to provide awareness and information on dementia. The first was in Stratford-upon-Avon in February.

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.

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Nothing to report for this quarter

Carers Trust

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

- Review the action plan taking account of the planned merger with the Princess Royal Trust for carers and its impact
- Review progress against carer specific clauses in Dementia Declaration:
- Encourage collaboration by our networks at local level to meet the aspirations of the declaration
- Monitor the web-based forum for exchange of practice issues around understanding and support of both people with dementia and family carers. Review any trends.
- Ensure that target for 60% of Crossroads Care staff achieving level 3 of the Qualifications & Credit Framework (QCF) dementia qualification is being met alongside staff turnover within schemes. Develop a plan for reaching marginalised and seldom heard from groups of people with dementia and carers
- Introduce principles of Dementia Care Mapping to enable person-centred care planning, ensuring, for example, that triggers to challenging or aggressive behaviour are recorded in care plans and that assessments and care plans are frequently reviewed to keep pace with the progress of the illness.

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During this period Crossroads Care Association has completed its formal merger with the Princess Royal Trust for Carers to form Carers Trust. This will act as the umbrella body for the complementary networks of Crossroads Care schemes and Princess Royal Trust for Carers centres. (Member organisations retain their familiar branding with the addition of 'Carers Trust – network member'). See www.carers.org

Plans are in hand, when re-organisation allows, to revise our declaration and action plan to expand them to reflect the role Carers Centres play in supporting carers of people with dementia. (Crossroads Care schemes continue to provide hands on support to people with dementia whilst providing carers with support, and time to themselves)

As regional DAAs are developing we are encouraging local network involvement. To date this is most developed in East Midlands where our local managers found the first regional meeting motivating and informative. They look forward to engaging with local networks as they develop and have now identified Dementia Champions. The development of regional DAAs will be a valuable catalyst to local progress.

Carers Trust is engaged with Carers UK and the Royal College of General Practitioners in the Department of Health's Supporting Carers Programme to help increase identification of, and support for carers throughout England. GP Champions, Expert Practitioners and Carer Ambassadors are being established. Improving professional awareness of carers in general will increase the likelihood of carers of people with dementia being identified and supported at an early stage.

Meanwhile Crossroads Care East Lancashire has received funding from the National Gardens Scheme to further develop its music therapy project for people with dementia through singing, and more Home Share projects have been established in East Cheshire, Wessex, North Wales and West Suffolk. Home Share provides daytime support, companionship and activities for small groups of people in the early stages of dementia, in re-assuring domestic settings, while family carers have a day to themselves.

Feedback from Crossroads Care Bexley's' dementia outreach project, which has a BME focus includes:

- Services (general) are **not offering enough cultural specialist support** e.g. activities, food (In one case a Jamaican lady was really made to feel excluded)
- Awareness of dementia is low; there is **still a lot of stigma and misunderstanding**
- Services are hard to access in early stages of dementia, unless paying
- Not enough knowledge of services available when diagnosed
- Waiting lists for services are too long
- GPs not informed when individuals become carers

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.

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The last three months have been very active – we have not only opened new homes, completed the recruitment of our specialist team of dementia trainers and entered the second year of our *Our House* project but we have also embraced Prime Minister David Cameron’s challenge to create dementia friendly communities.

New Homes

New homes have, or are about to, open in East Grinstead, Halstead and Copthorne, all of which have been designed around the lessons on the environment learned during our dementia strategy pilot study and from our work with Stirling University’s specialist in architecture and dementia.

The homes, which have amenities based around a ‘village green’, feature cosy lounges and dining rooms that mimic a domestic scale, floor to ceiling windows that flood rooms with natural light and gardens that are designed to reflect back gardens.

Specialist Dementia Training Team

The Board of Care UK has committed to rolling-out the experiential training, devised by Head of Dementia Services Maizie Mears-Owen, and other specialist training, across its 88 homes and 12 day centres as the improvement in resident wellbeing has been measurably seen to improve after staff receive training.

As well as experiential training for all staff working in homes or centres, the three-person team will deliver an introduction to dementia, training on the Mental Capacity Act and Deprivation of Liberty Safeguards, and ‘behaviour that challenges’.

The team, which will support a region each, hope the training will further Care UK’s commitment to reducing the use of anti-psychotic drugs as carers gain a

greater understanding of the effects of dementia and residents become more relaxed in an increasingly empathetic environment.

Our House

The *Our House* project, which is being trialed in Care UK's Lennox House in London, has entered its second year of working towards residents having a greater say in the running and direction of the home. The project also seeks to promote the importance of 'home' not just a physical place, but somewhere that you feel you belong, where you have a role and a contribution to make. Innovations in Dementia put forward the project and we are also working in partnership with Methodist homes.

Dementia Friendly Communities

To build understanding of dementia within communities Maizie Mears-Owens has undertaken the experiential training sessions with local fire and police services. It is hoped that this will be rolled-out across the country to promote understanding and empathy among officers who encounter people with dementia when they are at their most vulnerable.

In addition an increasing number of homes are offering drop-in support and advice services to carers in the community and offering not only their expertise but use of their facilities to provide stress-free outings for people in the community with dementia.

Culturally, Maizie is also leading a change that will see homes inviting the community into homes more frequently and recent successes have included a home that has become a venue to the University of the Third Age (U3A) and residents are enjoying joining-in art classes and proving a very keen audience for the music groups.

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.

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Nothing to report for this 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

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Nothing to report for this 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.

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- Published book 'Taking their side: fighting their corner – a collection of stories demonstrating the difference advocacy makes to the lives of people with dementia'. Free to download from the DAN website or you can order a hard copy
<http://dan.advocacyplus.org.uk/pages/resources.html>
- Held a national conference to launch the new publication, provide networking opportunities for advocates and share knowledge around evidencing the difference advocacy can make and how we can better communicate with people with dementia.
- Working with other national partners – OPAAL, AgeUK – on advisory board for project on role of advocacy in personalization, ensuring people with dementia are considered.
- Supporting people to develop memory books for people with dementia via Life Story Network Your Story Matters Project.
- DAN is currently looking for further funding to maintain and develop its services.

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.

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During the period February – April 2012, the Department of Health has made further progress in a number of the areas set out in its Action Plan, and has renewed its focus on dementia through the Prime Minister's Challenge.

- The Prime Minister's Challenge on Dementia was launched on 26 March 2012 and is an ambitious programme of work designed to make a real difference to the lives of people with dementia. By building on the achievements of the National Dementia Strategy, the ambition is to secure greater improvements in dementia care and research so that people with dementia, their carers and families get the services and support they need.

The Challenge is a challenge to the whole of society, as well as to government, the NHS and social care. It focuses on three areas:

- driving improvements in health and care;
- creating dementia-friendly communities that understand how to help;
- better research.

The Challenge sets out 14 key commitments across the three areas, together with further supporting actions.

A Champion Group has been established for each area, bringing together key leaders and organisations from across health, social care, the voluntary sector and industry to support delivery of the commitments in the Challenge and to mobilise wider engagement across society. The Champion Groups will report their progress to the Prime Minister in September 2012 and March 2013.

A communications strategy is in place that sets out the role of communications in raising awareness of the Prime Minister's Challenge and highlighting the progress and milestones achieved. This will play a key role in facilitating engagement with the public to seek their views on the Challenge.

- On 26 April 2012 the Design Council, in conjunction with the Department of Health, launched the project outputs from the innovation challenge Living well with dementia. The aim was to develop innovative solutions for those diagnosed with dementia to live a better quality of life. The five prototypes showcased at the launch were Dementia Dogs – providing assistance dogs for people with early stage dementia, BUDDI – a permanently worn discreet wristband to aid people with dementia, Trading Times – a web and mobile-based service for carers of people with dementia to help them find work that can be delivered on a time and location-flexible basis, the Scent Clock – a home scent device to stimulate appetite and enhance nutritional status in people with dementia and Groupele – a collaborative caring and sharing tool which enable the family to support their relative through easier, accessible communication. It is the intention that each project will shortly have in place next stage funding or investment partners.
- 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.
- 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.
- Guidance for the new dementia CQUIN goal to improve awareness and diagnosis of dementia in an acute hospital setting was finalised during the quarter for publication at the beginning of May. The CQUIN came into operation on 1 April 2012 and will be supported by a new data collection. In addition to the CQUIN, the Department is working with the NHS Institute on the development of a call to action on dementia care in acute hospitals.
- A range of DH-funded projects on the dementia workforce, covering both training for health and social care staff and training and support for family carers, completed their work during March and April 2012, and are currently being evaluated. The Department is currently developing an e-learning package on dementia that will be available free of charge to health and social care staff and expects to launch the learning modules in the summer.

Design Council

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

- We will launch and manage a national innovation competition that will demonstrate how good design can improve the lives of people with dementia and their carers through a portfolio of different projects.
- We will provide at least £350,000 of funding to partnerships of designers and dementia enterprises to stimulate innovation.
- We will research, write briefs for, and fund projects that focus on areas where innovation is most needed and can be most effective at improving outcomes.
- We will ensure that people with dementia and their carers are involved throughout the development of solutions.
- We will provide expert research, advice and mentorship to the people we fund to ensure the best possible outcomes.
- Design Council staff will support the projects in their early stages through volunteering and fundraising.
- We will record, showcase and disseminate the results of the competition to demonstrate and spread innovative new approaches to dementia care.
- We will evaluate and publish the results of the competition to quantify and validate the effectiveness of design-led innovation in this area.

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- Having funded and supported five teams to design products and services that improve the quality of life for people with dementia and those who care for them, the Design Council and Department of Health launched the resulting prototypes on 26th April.
- Videos, photos and information on all the prototypes can be seen at www.livingwellwithdementia.com
- Over 150 people from the worlds of policy, industry, social care and design attended a breakfast preview hosted by Paul Burstow, Minister of State for Care Services, and David Kester, Chief Executive of the Design Council on the 26th April where an exhibition of the five ideas was on show.
- An afternoon of livestreamed talks at the Design Council on the same day were attended by over 60 people and watched online by over 400. Speakers included Government Digital Services, Carers UK, Cisco, and Lloyds Pharmacy. Live content spread via twitter using the #dementiachallenge hashtag reached 2,238,078 twitter accounts with 4,953,015 impressions. Videos from the talks can be watched at www.designcouncil.org.uk/dementia
- The launch received a large amount of media interest with coverage including the Guardian, Independent, Telegraph, BBC News, Press Association, and many specialist journals and blogs. The design teams themselves were on BBC Breakfast (BBC1), BBC Radio 4 Today, BBC Radio 5 Live DriveTime, and BBC Radio Scotland.

- Independent forecast analysis of targeted social impact conducted by Baker Tilly indicate that these innovations could bring a social return of over £500 million, whilst the programme itself could generate £40 million of economic activity. These figures are based on a range of what are thought to be conservative assumptions.
- We are currently supporting the teams as they take their concepts into production, and are looking for further ways in which we can support and enable the use of design and innovation for people affected by dementia.

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

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Since our last progress report there has been significant additional work done which is designed to further improve social care services to people with dementia.

There has been work undertaken at both a national level, and locally by specific providers who are working hard to improve the quality of their dementia care.

Specific outcomes since the last progress report:-

- **The Development of Dementia Care and Support Compact:**
This compact was developed as part of the Prime Minister's Challenge on Dementia and has been signed up to by nine leading organisations and we are targeting at least 50 signatories by September
- **The establishment of a Quality Measurement Framework for Providers**
Several large providers have come together to establish some measures of quality within their services and these will be published by the provider organisation so that users, carers and citizens can measure their performance
- **Several large providers aligning their user feedback process**
Several large providers have also come together to unify their processes for getting feedback from service users and carers. This will enable much better comparative analysis across the system
- **The development of a Quality Care Campaign Website**

In conjunction with RDB Star Ratings we have developed a quality care campaign designed to advocate for improved quality within care services for people with dementia. We have set up this website and are in the process of developing the campaign and establishing key milestones

- The production of a Dementia Pledge on workforce skills and competencies
ECCA together with RDA have developed a dementia pledge on workforce and are now encouraging service organisations to sign up and publish their objectives and also to monitor their progress
- The ECCA Great British Care Awards ceremony celebrating good practice in care
The ceremony is taking place in central London on the 12th of May

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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- Completed our designs for a range of crockery specifically for people with dementia
- Located and visited a manufacturer in China to produce our crockery designs
- Met with lighting manufacturers in Hong Kong to supply the lighting technology we are developing for the dementia care environment
- We are now one of the 20 key sponsors of the Great British Care Awards. Whilst this is a commercial arrangement with the organisers, from the award

nominees perspective it's a fantastic way to recognise their hard work, achievements and to provide encouragement to them and others that they can and do make a difference.

- The Butterfly scheme continues to gather momentum

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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- 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 nearly 2000 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 125 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 158 criterion and it has also been aligned to latest government recommendations i.e. National Dementia Strategy as well as the CQC/RQIA/CI outcomes. This has ensures PEARL remains current and incorporates the most up to date best practices.
- 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 52 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 a development pack for new employees working within our dementia care homes that is aligned to the QCF 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.
- One member of the team has presented at the International Alzheimer's Conference in London.
- One member of the team has presented at the Community Care Conference
- We have continued to roll out the PEARL project with another 40 homes joining in March 2012

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.

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Nothing to report for this 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

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Nothing to report for this quarter

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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Nothing to report for this quarter

Housing and Dementia Research Consortium

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

The HDRC website has had further improvement and additions, including useful links and information on current research bids for members only.

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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The membership continues to grow. The network now numbers 48 associate members (Housing with Care providers or commissioners only) and 47 partner members (other interested organisations or individuals). During Sept-Nov 2011 the Research Coordinator visited several Housing with Care schemes belonging to core group members in order to assess the

provision for people with dementia. The case study schemes included one specialist or dedicated dementia scheme (specifically designed for people with dementia) and 6 integrated model schemes (people with dementia living alongside other tenants). This small-scale study has now been written up in a report titled: "Provision for people with dementia within Housing with Care: Case studies from HDRC Steering Group Providers". In terms of dissemination, in the first instance, the report has been emailed to all

Funding bids:

DALLAS (Delivering Assisted Living Lifestyles at Scale) competition: At the start of the final stage of the competition (Stage 3) there were 8 communities remaining, one of which included the HDRC. The final 5 communities will be made public on 23rd May 2012.

members and put on the HDRC website (in the next stage of dissemination it will be published on the Housing LIN website). This report highlights some of the differences in how schemes are tailored to support people with dementia and the need for more comprehensive information on how the needs of people with dementia are being met in Housing with Care. The future plan is to expand on this small-scale case study and apply the research at a larger scale across all the HWC schemes in the HDRC

Project title: "The impact of interaction with the outside community on the health and wellbeing of older residents in extra care and continuing care settings. Proposal submitted to The Dunhill Medical Trust. The outline proposal was successful and a full proposal has been developed and submitted for Apr 27th deadline (likely to hear if successful in Sept 2012).

Project title: "Developing best practice in social care and support for adults with concurrent sight loss and dementia within different housing settings". Full proposal submitted to NIHR School of Social Care Research. Final decision: mid may 2012.

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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Funding

- Jewish Care's community support and family carers' services continues to provide information to people with dementia and their families to explore affordable options for accessing services. In addition, our fundraising campaigns continue to strive to inform of the possibilities people with dementia have to live fulfilling lives. The Pesach (Passover) fundraising appeal was entitled *Help us bring freedom to those living with dementia*. This builds on the meaning of Passover when the Jewish people won their freedom from slavery. It successfully raised considerable funds to subsidise services for people living with dementia and at the same educated and promoted the ideas that people with dementia are entitled to:
"The freedom to be respected"
"The freedom to celebrate life"
"The freedom to be me"

Advocating on behalf of people with dementia

- A group of our homecare team in the Redbridge area have completed a programme of training to provide a new service to people living with dementia. They can provide 2 hours of one-to-one activity, in the person's own home, built around their life history and interests. This

provides an alternative to day centres and in some cases compliments it. As more people move to personal budgets providing this kind of choice becomes increasingly important. In July 2012 this training will be rolled out to home care workers in North West London. Volunteers are also being enrolled to join this course.

- VIPS champions continue to meet quarterly. The April 2012 meeting considered emotional challenges that individuals living with dementia face when they live communally in residential homes. Through this network Champions gain the opportunity to get fresh insights from one another and can explore ways to come closer to the real experiences of people living in our homes.
- Managers of our Day Centres for People with Dementia met in May 2012 to begin a process of planning services for the next 3 years. Personalisation and providing more choice are the most important topics on the agenda. We are exploring how to diversify from the traditional model of day services to bespoke packages that reflect people's personal interests. To survey and research with service users and their relatives is our agreed foundation stone.
- We have a schedule of Dementia Care Maps (DCM) to which care home and day centre managers have committed. The May meeting of Registered Managers had feedback from 4 care homes that have mapped in the first quarter of this year. Maps have been followed up with team meetings and action plans. DCM remains a very useful tool to help our staff and management to better understand what life is like for people in our homes and centres. Mappers, in turn, become the voice of the people they have observed during the maps.
- Jewish Care hosts a new *Singing for the Brain* group at Otto Schiff (Golders Green). This group was launched on April 23rd and has growing membership.
- A new dementia café was also launched at Otto Schiff on April 24th. It is called the *Memory Way Café* and has already established a core group of regular members.
- *Music for Life* completed an 8 week project at Vi & Jn Rubens House in Redbridge. 8 people with advanced dementia had the opportunity to find ways of expression through this project. The staff in the home were also able to use the project to develop and explore their own creativity and ways of communicating with the people who live in the home.
- Pam Turpin (ARUP employee and PhD student at UCL), has begun research at Vi & Jn Rubens Home to better understand the experiences of people with advanced dementia and multi-sensory impairments. Her research aims to explore interventions that can break through that potential "bubble of isolation" that can be associated with multiple disabilities.
- A group of senior staff from Jewish Care had a preliminary meeting with Andrew Chidgey (Alzheimer's Society) to explore how we, as an organisation, can work within the Jewish community to develop *dementia friendly communities*.
- Jewish Care held preliminary meetings with and plans to collaborate with *Dementia Adventure*. We aim to ensure that Jewish Care's

service users living with dementia will have genuine choice and support to achieve their preferences to explore nature and adventure.

- Jewish Care is about to launch a new collaboration with *Ladder to the Moon* at the Otto Schiff home in Golders Green. This will be an extensive project to set up “creative hubs” in the home that will provide networking opportunities, to link people living in the home with the local community.

Educating the workforce

- In May 2012 Jewish Care is holding the annual *Celebration of Success* event. Staff from across the organisation will receive certificates for their success in training and education programmes. 21 staff have achieved QCF levels 2 & 3 with the dementia pathway.

2 senior staff attended a train the trainer course for the DOH funded *Your Story Matters*. They have gone on to train a further 18 people in the organisation. All are working with individuals on their life stories. The impact has been exciting for people living with dementia and for the staff. We have plans to further collaborate with *The Life Story Network* to further develop and build on this initiative.

On May 18th we held a conference for staff and volunteers. 80 delegates attended “*A day to be Inspired*”. Workshops included themes such as:

singing, jewellery making, dance and exercise, drama and reminiscence.

It is also inspiring to report that a number of staff, on their own initiatives, are taking up degree courses on dementia with Bradford University.

Respite Care

- Exploring ways to offer more choice for overnight respite care remains high on our agenda. Our panning meetings with home care and day care managers are endeavouring to include new initiatives that could compliment our existing respite facilities that are located in care homes.

End of Life care for people with dementia

- The University College London/Kings Fund research project that was based at Jewish Care’s Lady Sarah Cohen Home is currently completing its report and findings. This includes a training programme for staff working with people with advanced dementia at end of life.

Upgrading and building residential and nursing accommodation

- We have begun work to build a new care home in North West London, with 54 beds, adjacent to the Lady Sarah Cohen and Rosetrees homes. The home will accommodate people living with dementia. Additional services will be included on this site to enhance services and

create a lively hub. A day centre facility will also be developed on this site. It is envisaged that the facilities will be completed within 2 years.

Assistive Technologies (AT)

- *Innovations In Dementia (ID)* are providing a number of training courses for staff and volunteers on the new on line AT guide for people living with dementia.
- The Dennis Centre and Vi & Jn Rubens home have begun to use *My Life Software* (interactive IT software for people with living with dementia). They have been collaborating with *My Life Software* to develop Jewish culturally specific programmes and will also take part in collating evidence of the impact of this product.
- Jewish Care was pleased to have been involved in supporting preliminary work with *Studiohead* (a design company) on developing a new IT networking site for the carers of people living with dementia. The concept is called *Groupie* and is still in proto-type. It was recently launched at the Design Council. *Studiohead* kindly presented the concept to a group of frontline community support and social work staff at Jewish Care.

Younger People with dementia in the Jewish Community

- Jewish Care's community support and social work services continue to support a small number of younger people living with dementia and their family members. This work mainly takes place on a one to one basis.

Joseph Rowntree Foundation

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

Our new 12-month scoping programme (April 2011-March 2012) 'Dementia and Society' will include three strands:

Strand 1: Scoping the current experience, and future needs, of people with dementia in the city of York.

Strand 2: Mapping user-led groups and organisations of people with dementia across the UK (project led by Mental Health Foundation, with Innovations in Dementia and Alzheimer's Society).

Strand 3: Exploring the scope for further work on other potential areas of activity - including best ways to disseminate, and in Bradford.

This work provide us with the evidence we need to inform decisions on whether to embark on a more ambitious programme of JRHT practice demonstration and/or JRF research and development in the future. We will also have had an opportunity to work in partnership with a number of local and national players.

Additionally, we will be publishing various outputs (project reports, Viewpoints etc) from the Better Life programme which relate to older people with high support needs and in some cases specifically to people with dementia. We also hope to launch a mini-website to showcase the lived experience of older people with high support needs through images, stories, case studies, DVD clips, poems etc.

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DEEP: Dementia Engagement and Empowerment Project

The DEEP project is drawing to a close (the Mental Health Foundation have been leading this JRF-funded national project in partnership with Innovations in Dementia and Alzheimer's Society). The final report (including an accessible version and a short film) will be launched at the NCAS conference in October 2012. The project has found that the collective voice of people with dementia is at a relatively early stage. However user-led groups are growing in number and confidence. They ask for support in capacity-building, networking and learning from each other so they can increase their influence over attitudes, policy and services. The partners involved in DEEP are currently discussing how to respond to these findings and provide further input and support.

'Dementia without Walls'

Our other main project – the York-focused 'Dementia without Walls' - led by the consultancy, Aesop (Janet Crampton, Janet Dean and Ruth Eley) is also

in its final stages, with a sounding-board event in York on 24 May at which all those involved will help to shape the emerging messages. There is huge interest in the project both nationally and locally, especially since it was cited as a case study in the PM's Dementia Challenge report and in the Alzheimer's Society 2012 report. The project has highlighted much scope for supporting local communities, organisations and businesses to become more aware and understanding of dementia, and more inclusive. Our final project report will be published in September. Our involvement with the PM's Dementia Challenge Champions Group will enable us to share lessons from the York project and to learn from others engaged in similar endeavours.

Other progress

Three short Viewpoints commissioned from key thinkers in the field will be published in due course. It is hoped that these will offer challenging and individual perspectives on how dementia is perceived in our society, and a useful stimulus in our scoping work.

Numerous other meetings, events and contacts have also been contributing to our thinking and scoping around dementia. These include the Dementia Action Alliance (DAA) event, Alzheimer's Society State of the Nation event, UK Dementia Congress, and Guardian online panel debate.

We are holding a dementia round table in Bradford in May, and in Wales in July. We have also signed up to our regional DAA (Yorkshire and Humberside).

Joseph Rowntree Housing Trust

In addition to our routine care service and activities, JRHT has:

- Been planning further dementia awareness workshops for WRVS following the successful pilot in Sheffield
- Completed the delivery of the knowledge workshops for North Yorkshire County Council's Dementia Champions project.
- Launched the Unique Ambassador programme for our own care staff. The 12 staff selected have already been involved in the launch of our work on excellence, and are now commencing the dementia training aspect of the project in June. This includes completion of an accredited dementia care qualification which is at a higher level than that previously offered to frontline care staff.
- Launched a co-production project to develop an excellence framework for all our care and support services. This will include gathering the views of people who use our services about what is required to live a good life when you have care and support needs.

Planning for 2012-2015

We are currently finalising our proposal for a new programme of work called Dementia, Community and Society, which (subject to approval by our Trustees) will run until 2015. The difference we want to make can be summed

up as: “People living with dementia are more understood, more heard, more included, more connected and more supported – with and by each other, their local communities and society as a whole.” Our core questions are:

- How does society as a whole need to change to support the growing numbers, diversity and aspirations of people affected by dementia?
- How can our local communities change to be better places for people with dementia to live, and live well?
- How can our own organisation be part of this societal shift, and part of making York a dementia-friendly city?
- How can people with dementia better connect with and support each other, so their experiences can shape policy, practice and attitudes?
- We will be able to report in more detail on the future of our programme in the next quarterly report.

Ladder to the Moon

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

- Delivering high quality creative culture change programmes in residential and housing settings
- Delivering communication and relationship training for front line care staff
- Programmes to support activity roles to see themselves as activity and occupation leaders
- Transformational and inspirational workshops at care provider conferences
- Coaching managers to lead change
- Influence thinking, attitudes and practice at local and national conferences
- Partner with other pioneers in the field

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- Delivering high quality creative culture change programmes in residential and housing settings
- Delivered 10 programmes including 5 funded through Skills for Care Innovation Funding. With a total of 120 staff
Programmes to support activity roles to see themselves as activity and occupation leaders Completed 2 programmes with 24 Activity Leaders and 24 Manager
- Transformational and inspirational workshops at care provider conferences
- Delivered workshops at the Milton Keynes Social Care Conference
- Coaching managers to lead change
- Coached 10 Care Homes managers
- Partner with other pioneers in the field
- A number of meeting exploring possibilities, hopefully an announcement next 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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- Establish a national network of trainers through the facilitation of a managed learning network utilising action learning, coaching and peer support;

Achieved:

Trainers from the Your Story Matters project are linked in to a virtual learning environment offering peer support through a private discussion forum. The network will continue to work with these trainers to support further roll out of life story work.

- 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.

Achieved:

Your Story Matters project:

There was an overwhelming response to the publicity for the courses, nearly 250 people applying for the introductory courses and 224 for the 50 places for trainers.

76 people have been trained at the introductory workshops and 50 Trainers have been trained who have gone on to train up to 10 people each within their own organisations. Trainees have come from a range of professional backgrounds as well as volunteers and family carers and from all regions.

The project has therefore succeeded in its objective of reaching people working in a variety of settings across health and social care and including volunteers and carers

- 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.

Achieved:

Through the trained trainers the Life Story Network has engaged with senior managers to ensure support for front line staff carrying out this work and also understanding that relationships form the basis of person centred care.

Other organisations have commissioned LSN to engage with senior managers to embed the learning from this work within the culture of their organisation.

- Disseminate learning through a variety of media.

Achieved:

The internal evaluation for the project is just being completed and we intend to publicise this widely.

- Conduct an on-going evaluation of the work with our existing research partner, the Social Policy Research Unit at York University.

Achieved:

SPRU at York University are conducting an external evaluation which will be published in July. To date we have provided data for the evaluation from all the course participants.

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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Nothing to report for 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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Nothing to report for this quarter

Lost Chord

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

- Looking into innovative schemes to raise funds to finance the scheme throughout the country.
- Applying for grant funding to support the research into the effect of music on the brain particularly into the care of those suffering with dementia.
- Organising training courses which could be accessed by carers on the effects and use of music as a necessary intervention in the care of people living with dementia.
- Looking into the possibility of a seminar for alternative therapies effective in the care of dementia

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- Attended the Great British Care Show in York on 2nd May where I was invited to speak about the impact of music on people with dementia and its importance in future dementia care, particularly in the light of the successful reduction of antipsychotic drugs which was highlighted by the campaign last year of the Dementia Action Alliance.
- This gave rise to the opportunity to promote the present campaign for early diagnosis. The next Great British Care Show is in Brighton on 30th May where there will be another opportunity to promote the DAA's achievements and aspirations for people with dementia.
- Still awaiting the outcome of the funding application to Awards for All, however if we are successful in securing this funding and setting up 4 new dementia cafes, I hope this will be a model to work closer with the Alzheimer's Society particularly linking in with their singing for the brain scheme. Alternative therapies and in particular music is now of crucial importance with the reduction of antipsychotic drugs throughout the UK.
- I have been successful in securing funding of £50,000 for Lost Chord's work for people with dementia, from The May & Stanley Smith Charitable Trust in the United States. An integral part of the application and indeed any application made by Lost Chord is our membership of the DAA and the importance of its work in the field of dementia. Making particular reference to the recent campaigns was an opportunity to further promote the success of the DAA outside the UK.

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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- Completion of the Dementia Choices project in 2011. All four projects have submitted their final reports. These reports, together with a summary of the scheme will be made available in June 2012.
- issues affecting people with dementia are included in our on-going project work on mental capacity issues.

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 Foundation is providing a training and consultancy service to help organisations successfully implement the Mental Capacity Act. This could include care homes and voluntary sector organisations as well as the NHS and local authorities. For more information contact Toby Williamson at twilliamson@mhf.org.uk.

- Seeking funding for further research into quality of life

The Mental Health Foundation has 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. The Group Facilitator is now in post and we are hoping that the first group will begin at the end of July.

- practical ways in which our services can be adapted

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/>

- Dementia Engagement and Empowerment Project (DEEP)

The project is now complete. Two events were held for people living with dementia in London and Stockport. Almost 50 people living with dementia attended together with family and supporters. Both events were filmed and both the final report and the film will be available via the Joseph Rowntree Foundation in the autumn. All the organisations involved in DEEP are keen to find ways to supporting the growth of groups involving people with dementia in the future. Presentations about DEEP were given at the Scottish Dementia Congress in March.

Information about some of the groups is contained on a map showing where these groups and projects are: <http://www.mentalhealth.org.uk/our-work/research/research-projects/dementia-engagement-and-empowerment-project/?view=Standard>

- evaluate an innovative educational programme for family carers

The two programmes have finished and the evaluation has been completed. The evaluation report is currently with Dementia UK.

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 Person Inside - Dementia Awareness Training continues to be delivered at all homes and schemes caring for residents and tenants living with dementia.

- MHA continue to maintain their commitment to Dementia Care Mapping. In February 2012 a further 28 members of staff have been trained to undertake Dementia Care Mapping.
- The dementia resource box which has been developed by the MHA training department is currently being piloted and a full roll out is planned for late summer 2012. It is anticipated that the resource box will be jointly badged by Bradford University prior to the full roll out and implementation.
- The pioneering work of using Music Therapists within MHA homes caring for people with dementia continues. A total of thirteen Music therapists are now employed across MHA projects.
- MHA continues to maintain their commitment to research into the care and support of people with dementia with their on going relationship with the Housing and Dementia Research Consortium.
- The work within MHA of addressing the reduction of antipsychotic medications in care homes continues and a policy specifically addressing the management of Antipsychotic medication in MHA care homes is currently being finalised. The progress of antipsychotic medication usage reduction across MHA care Homes will in future be monitored via the organisations central care monitoring program.
- MHA continue to review and monitor standards within all homes and housing with care schemes using an in house standards assessment. This continues to identify high levels of compliance against all standards associated with the utilising of a consistent person centred approach to care. Other activity listed in our Action Plan is on-going.

My Life Software

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 public sector 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.

Our list of events to be attended in 2012 to help promote awareness is growing and we are publishing new case studies.

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 Programming environments to help increase availability of DRTS.

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's membership has increased to 2,682 members an increase of over 200 from the last report. All members receive 8 magazines a year that share ideas and best practice as well as recognising the achievements of care home staff. We encourage our members to ensure all staff, whatever their role, to contribute to the 'activity life' of residents. This is particularly important in dementia care where the most fleeting interaction can have a lasting effect on someone's well-being.

Sales of our books, collectively called the NAPA Activity Toolkit, continue at a steady pace. The new Living Life for Relatives and Friends has been well

received and we will continue to offer ideas for making visits to the care home more enjoyable for all. Our new qualification, which includes a specialist unit on Dementia, is slowly taking off. Along with our bespoke training days we are seeing a marked decrease in requests for training, through pressure on care home budgets, which we are concerned about. Knowledge and skills can make a real difference to the level of care offered in dementia settings. Our NAPA 'Go for Gold' Challenge, in conjunction with the British Heart Foundation and many other partners, was launched in February. Care homes around the country are now 'in training' for the Challenge week starting on Sun 1 July. This will promote the importance of physical activity for older people including people with dementia.

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.
- 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 Annual Conference takes place on the 22/23 May 2012. A workshop regarding the work of the DAA has been included in the programme. An entry has been written for inclusion in the NCF Annual Review Book which is given out at the NCF Annual Conference. The Annual Review is also circulated to a wide range of key stakeholders
- 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. Planning is in hand for November 2012.

- NCF have facilitated a tour (May 2012) from colleagues in Sweden to see services in the Wiltshire and Bristol. These include best practice initiatives in relation to dementia care.
- Dementia Services remains a key topic for the NCF Practice Forum.
- The Order of St John Charitable Trust (an NCF member) now has two Admiral Nurses. 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. The next EAHSA Conference takes place in Malta in September 2012. Likewise NCF are the English chapter of IAHSA.
- Sharon Blackburn with Prof Julienne Meyer and Barbara Stephens have presented at the Community Care Live Event 2012 on: My Home Life Movement concerning 'Living alongside Dementia'- perspectives from residents; relatives and staff.
- In June Sharon Blackburn will be presenting at the Hammond Care Dementia Conference -Risky Business Conference in Australia.
- 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. Phase Two is commencing with the testing of the prototypes.
- NCF members are continuing to press ahead with innovative approaches to dementia care and the lived environment. Somerset Care and Joseph Rowntree are both engaged in projects regarding Dementia Friendly Communities.

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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- NCPC attended the Alzheimer's Society annual conference on 26th March, where the Prime Minister David Cameron made a personal commitment to tackling the 'dementia challenge' and launched the new document *Prime Minister's challenge on dementia*. We were very pleased that No.10 decided to put its weight behind improving dementia care and research, but disappointed that the document did not make explicit reference to the

importance of palliative and end of life care in dementia. We and other organisations felt this was a missed opportunity as we have been working so closely together to join up the implementation of the End of Life Care Strategy with the Dementia Strategy. Subsequently NCPC wrote to Number 10 with Age UK, Dementia UK, Help the Hospices, the National Care Forum and Sue Ryder to offer our organisations' help to ensure that the Dementia Challenge delivers improvements in the care of people with dementia right until the end of life. We are delighted that the challenge now includes end of life care and we are part of the Dementia Health and Care Champion Group. We and our partner organisations will now work hard with the Prime Minister and DH to make this a reality. Read more at www.ncpc.org.uk/news/93

- NCPC submitted evidence to the All Party Parliamentary Group on Dementia which is undertaking an inquiry into dementia diagnosis rates in the UK. Our evidence focused on the fact that people need an early diagnosis in order to understand what is happening to them, get access to the services they need, and to plan for the future while they still have the capacity to do so, including for their end of life care. You can read our evidence at www.ncpc.org.uk/page/consultations
- NCPC's Dementia Group, a cross cutting group of representatives from dementia, social care, housing and palliative care organisations, met on 11th April to discuss its next steps. Karen Harrison-Dening updated the group on work undertaken by Dementia UK to train primary care staff in advance care planning for people with dementia. This work linked well with Dying Matters GP training project which is entering a 'train the trainer' phase. The group also heard from Dr Paul Schofield, from NAPP Pharmaceuticals, who spoke to the group about the problems surrounding piloting pain management medication with people who have dementia. A number of actions were identified to be taken forward.
- We welcomed the DH and Alzheimer's Society new programme of work on dementia friendly communities, and have offered our support to develop it. Our contribution will build on our 2030 Vision, which highlights the need to develop communities fit for purpose to support the growing numbers of older people and people with multiple long-term conditions living and dying in the community. We published a report on this in February with fellow DAA members the National Care Forum. Read more at www.ncpc.org.uk/news/85
- NCPC's Policy & Parliamentary Affairs Lead Alice Fuller attended the *Living well with dementia* exhibition event on 26th April at the Design Council. She spoke to designers of five innovative products developed to improve the lives of people with dementia and their carers, and challenged the panel to think about how innovative design can be used to help people to plan early and to enhance quality of life in the later stages of the condition.

- Preparations were underway for the third annual Dying Matters awareness week (14-20 May), which aims to get the nation talking about dying, death and bereavement. www.dyingmatters.org

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 national partners (Innovations in Dementia) and local partners in each of our four pilot sites, continued to develop and implement the **Circles of Support for People with Dementia** project over the past quarter (more information on the project can be found at <http://www.ndti.org.uk/major-projects/circles-of-support-for-people-with-dementia/>).

Over the last quarter this has involved:

- Setting up more Circles of Support with people with dementia, and their families and friends, in the four areas where the project is running. There are now 9 individual Circles of Support which have either been set up or are about to start. Through this work we're meeting and working with a

diverse group of people, many of whom want to change the support that they get to enable them to do different things. Individuals' goals range from going sailing, being able to go back to watch motorsport again, joining a new gardening club and finding new friends. We're finding that this approach is helping to enable a wider group of family members and friends to become more involved in directly supporting people living with dementia to meet their goals.

- Running a workshop on this project at the Alzheimer Disease International conference where we met with some truly inspirational people and also made some good connections with people in organisations promoting volunteering to help increase support for people with dementia and enable them to live well in their communities.
- Continuing to look for and discuss opportunities to work with other organisations and groups within this project – both within the four site areas and on a national basis. Examples include CSV, the National Council for Palliative Care and Timebanking UK.
- Planning and designing an open day about circles of support (and other individual planning tools and techniques) and understanding dementia for family members and the wider local community in one of the 4 sites. The aim of this session is to help neighbours, friends and wider family members who may not be so involved in more in-depth caring roles to become more familiar and confident about dementia and how best to support people; and to find out more about circles of support as a very “family friendly” way of supporting people with dementia to live well through person centred planning.

Over the last quarter we have also :

- Started two exciting new pieces of work which are all about coproduction with older people who need support in their lives, including people living with dementia. This includes people living at home, in sheltered or other forms of supported housing, residential and nursing homes. Firstly NDTi and Hampshire County Council are working together to establish a commissioning co-design project involving older people with high support needs who live in different parts of the county, to coproduce a new commissioning strategy focusing on the different kinds of support that people want to have a good life. Secondly, we are working with older people and people with a learning disability living in and using care services provided by the Joseph Rowntree Housing Trust, to coproduce a new guide for excellent support – which will be used by both people living in and using JRHT services and staff working in those services. A central concern and priority for both these initiatives is finding different ways for people living with dementias to be part of these developments, contributing their experiences, views, skills and advice to ensure that future support helps them to live their life. As someone in the Circles project says: ‘dementia is life changing – it shouldn’t be life ending’.
- Reached the final stages of the Not A One Way Street research project which we referred to in our last update (more information on the project can be found at <http://www.ndti.org.uk/major-projects/not-a-one-way-street/>). This action research project has focused on exploring older people’s access to and experiences of support based on mutuality and

reciprocity. We have found some fantastically diverse and inclusive forms of support through this research – often “under the radar” supports that have evolved organically and on a very small scale to support people with a wide range of high support needs in a truly individualised way. Homeshare and Shared Lives schemes for people living with dementia have shown to be an effective way of helping someone to retain their relationships, interests and roles in family and community life whilst avoiding crises and maintaining good physical and mental health whilst adjusting to life with a long term, degenerative condition. We are holding a Sounding Board event in York on 29th May to share our findings and conclusions; if anyone from the DAA would like to be involved please contact Claire.Jones@ndti.org.uk or Helen.Bowers@ndti.org.uk for more information and an invite!

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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- The draft scope for the pilot social care quality standard on dementia care was consulted upon during Q4 2011/12
- The second Topic Expert Group will be held on 14th/15th May 2012
- A full pathway guide for commissioners on dementia care is proposed for the 2012/13 work programme. This will update and encompass previous guides on memory assessment services and end of life care.

National Skills Academy for Social Care

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

We are addressing these challenges by developing and delivering an extensive engagement strategy, and we are already increasing our membership to include more employers that support people with dementia and their carers. (see enclosed bulleted list for additional information). We are also working with our members to ascertain how best to support them in their leadership capacity. We work closely with our partners such as Skills for Care and the Social Care Institute for Excellence, to provide a unified voice in the social care employment sector. We have been commissioned to develop a Leadership Strategy by the Department of Health which will be launched in the autumn. The strategy will include a Leadership Qualities Framework on the essential leadership qualities needed to deliver best practice in social care, including care for people with dementia.

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The National Skills Academy takes the lead in providing direction and guidance on leadership development in social care. Our aim is to help employers, managers, trainers and commissioners to deliver better care by improving leadership behaviours at every level of the social care workforce.

In terms of progress against the commitments we have made to support the delivery of outcomes for people with dementia 2011 – 2014:

We have further developed our range of leadership development programmes, to include people working in roles at senior and middle management level alongside Front-Line leaders, and we are in the process of rolling these out nationally. Many of the organisations who have taken up the programmes have a particular interest in dementia issues. They include Abbeyfield, Barchester, Jewish Care and Bupa Care Homes.

We are rolling out a new programme designed to improve commissioning practice, *Commissioning Now*, in early June. The programme includes commissioning for older people's services, and aims to provide participants with a comprehensive guide to excellent commissioning in practice, alongside practical strategies for how to attain it. We also have a range of good practice case studies in commissioning user-led services.

As a corollary, we have a leadership development programme for new Directors of Adult Social Services, which is starting in May 2012 and is designed to include commissioning of services for older people and specialist commissioning of dementia services.

We are rolling out our Endorsement Framework to recognise and badge excellent social care training provision. We now have over 70 Recognised

Providers and 14 Centres of Excellence around the country, and many of our trainers specialise in working with people with dementia. Our Framework also supports effective commissioning of training.

We will be launching our Leadership Strategy for Adult Social Care in the wake of the launch of the Social Care White Paper in June. The Strategy will include a Leadership Qualities Framework to set out essential leadership qualities and behaviours to ensure best practice in social care, including care for people with dementia.

We have engaged widely with the sector to promote good practice in the care of people with dementia, partly through an open membership scheme that now covers thousands of care homes, home care services and other support services around the country, alongside training providers, charities and local authorities. Some 70% of our members are employers, and many of them specialise in care of people with dementia. At the same time, we have promoted good leadership as a vital factor in the delivery of quality care at a range of external conferences looking at the care of older people, and we have supported the Care and Support Alliance, and Age UK, in their campaigns earlier this year around appropriate funding for social care.

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.

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Nothing to report for this quarter

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.

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Update on Commission on improving dignity in care for older people

The Commission on improving dignity in care for older people has now completed consultation on its draft recommendations. There was a large response to the consultation with over 230 written responses from national and regional bodies, service providers and commissioners, local authorities, academics and members of the public. In addition to written submissions many nurses participated in consultation events, doctors commented through our clinical reference group, and an academic reference group reviewed the evidence. In response to the consultation the Commission is currently drafting its final report, which is due to be published this summer. The next phase of this work will focus on translating the recommendations into an action plan.

NHS Institute for Innovation and Improvement

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

Plan for raising of awareness of the problem – the potential harm of prescribing antipsychotics for people with dementia and better understanding of safe and effective alternatives and improved team working:

1. Call to Action launch (June 2011) –national launch across all commitment groups and supported by the Dementia Action Alliance (co-branded, please see supporting material)
2. Specific focus on each commitment group, led by the National Taskforce for Dementia and Antipsychotics:
 - Junior Drs Induction pack on antipsychotics and dementia (launched August 2011, follow up Sept 2011)
Royal Pharmaceutical Society annual conference, Sept 2011 (includes RPS/ITN film that has been made to highlight the issues)
 - Leader in Care homes: targeting independent providers – Sept – Dec 2011; Care Home focus week planned for January 2012
 - GPs and Primary Care – engagement of 22,000 GPs planned through the use of Drs Net virtual platform (Nov 2011 – Feb 2012)
 - Regionally based workshops for implementing the Call to Action (based in Strategic Health Authority areas, Sept 2011– Jan 2012. These will include planning for sustainability)
Intensive coaching to support Call to Action implementation and how to secure commitment and action (Sept 2011- Feb 2012)
 - Presentations at regional Medical Directors Forums (Sept 2011 – Jan 2012)
Support for regional implementation of the Commissioning Pack for Dementia (9 out of 10 regions confirmed) Sept 2011- Dec 2011.
 - Development of the Call to Action website and online community – a virtual space where all activists can come together to share best practice and access resources and expert content (July 2011 – ongoing).

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- To support the implementation of the Dementia Commissioning Guide the Call to Action has been directly presented to over 1500 people.
- An economic cost-benefit analysis of the use of antipsychotics versus Cognitive Stimulation Therapy was commissioned and it highlighted that antipsychotics are not a cost effective use of public money. This has been

disseminated nationally and helps commissioners and other to consider the economic argument for developing alternatives to antipsychotics.

- An Education support programme has been developed for Junior Drs and Hospital Teams and had its first 'roll-out' in August 2011 to coincide with the new junior doctors' intake. It went out to all NHS England Medical Directors, 70% of whom reported that they were able to use it their hospitals. The use of this, and the learning from it, will be further extended.
- The Drs Net continuing education campaign based around the Dementia Call to Action- and the first of its kind – was launched on Drs Net in Dec 2011 and will run until June 2012. This will target 'engaged and active' GPs to help them improve their understanding of BPSD and the alternatives to prescribing antipsychotics, as well as enabling them to test their knowledge and report on their clinical review practice. The early information also supports key challenges around early diagnosis and the difficulty some GPs express around beginning the conversation about a possible diagnosis of dementia with patients. The target 'engagement' for the 4 months that the site is in operation is 5000 GPs. The data collected from the GPs use of this site can inform increasing their engagement over the next 12 months. A poll of 200 GPs showed that just over half knew the reasons that patients were prescribed antipsychotic medication in the first instance with a another poll showing that three quarters of GPs intended to carry out a medication review for their patients. As part of the developmental quiz (711 participants) on the microsite a number of key themes emerged in terms of gaps in knowledge. Specifically, these are around knowledge of the drugs and licensing, understanding of the drugs and the scope of the NICE guidelines. Future plans for the Doctors.net contract are intended to address these gaps.
- We have co-designed and produced a resource with front line community pharmacists ,Gps and the Royal Pharmaceutical society to enable 40,000 community pharmacists make their contribution to the call to action This resource will support pharmacists Medicines Use Reviews and to enable clinical practice to be reviewed and changes to prescribing of anti-psychotic medication to take place. The resource also contains an education and audit component .This resource will be launched over the summer as part of the RPS alert programme
- We have successfully brought together the leaders of the major care home providers in England and secured commitment to share information about improving practice in care homes and audit data. Many care homes have worked in partnership with the large pharmacy providers (eg Boots) to undertake medication reviews of people living in care homes on antipsychotics. In an audit of 1990 care home residents living across 7 different care organisations – 72% of them have had a clinical review (since May 2011), 236 (11.85%) have had antipsychotics reduced and 500 (25%) have had them stopped. Audit has shown that those who have not been able to discontinue antipsychotics are people who have a co-morbidity that would indicate the use of antipsychotics (such as

schizophrenia) or have very high levels of BPSD and are complex cases, under continuous monitoring by a consultant psychiatrist. This work can be extended further.

- We have connected with the Chief Nursing Officers in England to link with potentially 25,000 nurses and mobilise them as part of the acute hospitals group,
- A vibrant and growing online call to action community network (700+ active members) is harnessing the power of social media – providing direct access to National Leaders and enabling busy activists to link with each other and share audit, examples of best practice, local protocols and guidance and has informed the development of local CQUINS. Delivery of an expert webinar series attracting over 1200 registrants .

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 we are continuing to bring about greater consistency and quality control of its services. The newly formed Operations Team and Service Development Team continue to work in partnership in order to deliver on our agreed action plan to improve our dementia services.

The new audit tool was distributed to all Home Managers in January 2012 with the opportunity for homes to achieve accreditation in dementia care based on the lived experience for the person with dementia. Emphasis placed on the home community atmosphere, occupation and a dementia friendly environment. Identified dementia communities are being supported to achieve accreditation.

The work with the Design Council is completed and as an organisation we are continuing to prototype capturing 'real time' feedback with the use of flip cameras to capture the views of residents, relatives and staff. Following the evaluation of this piece of work it will be shared with other homes within the organisation.

Our Admiral Nurse and Dementia Development Lead meet with all of the homes Dementia Leads across the organisation quarterly. Dementia Leads are able to share good practice ideas and are encouraged to set personal goals to achieve each quarter. Information and good practice is promoted and cascaded down into the homes.

The Service Development Team continues to work alongside the Operations Team to develop therapeutic dementia communities' identifying orientation aids and the use of colour, lighting and signage. This will further support the new Dementia Accreditation in our audit tool.

The Service Development Team and Operations Team will agree a number of homes where key senior staff will support home staff to develop their person centred care practices and the environment in order to ensure a high quality service are provided.

With support from our Admiral Nurse and Trust Advisor we continue to monitor the use of anti psychotic medication and sleeping medication within our homes to ensure minimal use as necessary.

The Service Development Team has produced our Trust in Dementia Care Booklet and DVD to support and give valuable information to relatives and carers. The homes Dementia Leads are taking responsibility for the launch and promotion of this booklet in their own home.

Parkinson's UK

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

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

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Partnership and Engagement Officer to lead work on raising awareness of Dementia with Lewy Bodies (DLB) and Parkinson's Disease Dementia (PDD) – a joint appointment with the Lewy Body Society -- began work in February 2012.

- Work has begun on gathering information for the 2013 revision of Parkinson's UK's information resources for people affected by PDD and DLB.
- Participating in James Lind Alliance dementia research priority setting exercise.
- Submitted joint response with Lewy Body Society to NICE scoping for consultation on Social Care Standard on Care of People with Dementia (April 2012)
- NICE has confirmed that the guideline for Parkinson's will be reviewed following submissions from Parkinson's UK and other parties. We will use this opportunity along with the development of NICE Quality Standards to raise issues around Parkinson's disease dementia and dementia with Lewy bodies.
- Working with Dementia UK to revise internal training on DLB/PDD for staff who provide direct support to people affected by dementia and those who educate health and social care staff due for roll-out in October 2012.

We aim to ensure that Lewy Body dementias are included in the national dementia awareness campaign planned for autumn 2012.

We have been campaigning for fair access to comprehensive, high quality Parkinson's services across the UK.

Parkinson's UK have provided the Research Grant administrative support for two 'Innovation Grants' for studies into Dementia with Lewy Bodies funded by Lewy Body Society. One study uses stem cells cultured to function like neurones in the cortex; the other is into the genetics of neurodegeneration.

Professor David Burn at the University of Newcastle is currently conducting a study funded by Parkinson's UK entitled: 'Does the Parkinson's 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.

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Nothing to report for this quarter

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

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Nothing to report for this quarter

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.

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Nothing to report for 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.

Over the last two years, the RCGP's has been focused on 3 areas which are outlined below; these have been facilitated 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.
- 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.

However Professor Robinson's role ended in December 2011. Fortunately for the Dementia Alliance, the RCGP has recommended dementia as one of its clinical priorities for 2012-2015. This will mean the appointment of a RCGP national clinical champion in dementia who will develop, with the college, a targeted programme of work in this area.

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

These interviews have been held in March 2012 and we are delighted to inform you that Dr Jill Ramussen, a London- based GP, and Professor Louise Robinson, an academic GP in Newcastle have been appointed to share this exciting role. Jill and Louise came in to post in April 2012 and are currently

developing their work plan for the Dementia clinical champion role 2012-2015
– further details of this will be summarised in the next update for the Alliance.

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.

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The RCN continues to share and promote the 'Commitment to improve care for people with dementia in general hospital settings' launched last year.

The Commitment acts as a guide to support the delivery of dignified care for people living with dementia and their families. It sets out five key principles 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. Staff who are skilled and have time to care.
2. Partnership working with carers.
3. Assessment and early identification of dementia.
4. Care plans which are person centred and individualised.
5. Environments that are dementia-friendly.

Further information about the commitment including how to access resources such as pocket guides, posters, pens and mouse mats, is available on :

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. This has received over 60,000 hits over the last 8 months since its launch.

Next steps:

1. At the RCN Congress w/c 14th May 2012 which has attendance of 4,000 delegate upwards we will be sharing resources and information about dementia within presentations and events.
2. A best practice gallery will be launched w/c 14th May 2012 to share innovative practice for people with dementia in hospitals.
3. An educational resource to support practitioners in making positive changes to their practice including a DVD / web-based film of people with dementia family carers and practitioners along with a supporting 'how to guide' will be launched in the Summer 2012.
4. Regional workshops will be delivered in Autumn 2012 to disseminate the new resources

Royal College of Physicians

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- 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.

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Since our last report the Royal College of Physicians (London) has:

- Met with Alastair Burns after a meeting at Alzheimer's UK HQ regarding an update on the PM's challenge.
- A new Clinical Fellow has been appointed to work with RCP-doing some work on dementia, liaising with Alastair Burns.
- We have been supporting the next stage of the previously mentioned project on use of anti psychotic medicines in care homes.
- Our 'Future Hospital Commission' will take 'care of people with dementia in hospital' as a cross cutting theme

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

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Nothing to report for this quarter

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.

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Nothing to report for 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?

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NAAPS UK has now rebranded at Shared Lives Plus - please could you amend your records and publicity. Our contact details have changed from alex@naaps.org.uk to alex@SharedLivesPlus.org.uk and our website is now www.SharedLivesPlus.org.uk.

Progress:

- We have supported the dissemination of learning from the national dementia and Shared Lives project, hosted by SWAPS Shared Lives service.
- Kent University has commenced it's research into the outcomes of Shared Lives with older people, working with three of our member Shared Lives schemes.
- There was an article about Shared Lives and dementia in the Journal of Dementia Care.
- We have been working on a major funding bid for development of Shared Lives for older people and those with dementia.

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

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Nothing to report for this quarter

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.

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Nothing to report for this quarter

Social Care Institute for Excellence

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

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

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1. SCIE will further develop and promote the Dementia Gateway to new and existing audiences

Progress:

- Work to restructure and redesign the Gateway, to expand its content and enhance usability for a range of audiences is underway.

- New sections ‘Working in partnership with carers’, ‘Early signs of dementia and getting a diagnosis’, and ‘Post-diagnosis support’ are completed and will be added to the site following the redesign.
- New section ‘Dementia and sensory loss’ is in development, in partnership with RNIB, SENSE, Royal Association for Deaf People and Thomas Pocklington Trust.
- Work to add content about new research findings and opportunities to participate in research is being explored in partnership with DeNDRoN.
- Work to add a research narrative to each section of the Gateway is underway.

2. SCIE will undertake further work on end of life care for people with dementia

Progress:

- Research briefing **End of life care for people with dementia living in care homes** is complete and will be launched at the end of May, together with an At a Glance summary.
- 3 Social Care TV films about different aspects of end of life care will be launched at the same time.

3. To maximise choice and control for people with dementia and their carers, SCIE will continue to develop products on personalisation

Progress:

- Work to review and update the content of SCIE report 20 – **Personalisation: a rough guide** is ongoing, and will ultimately result in a new digital product that links the updated content with other relevant SCIE resources and valuable work from other organisations.
- 3 new Social Care TV programmes have been developed looking at integration, micro-enterprises, and risk enablement in the context of personalisation
- An At a Glance summary looking at personalisation for older people from black and minority ethnic communities is being developed.
- Work on a SCIE research briefing **Personal Budgets – outcomes and effectiveness in social care and health** is underway, and includes a specific search for evidence of how personal budgets are working for people with dementia.

4. SCIE will continue a programme of work to support the workforce to understand and implement the Mental Capacity Act

Progress:

- Pilots were carried out using the MCA training materials with managers of residential and domiciliary care and supported living services. Feedback was also invited from SCIE MCA training associates. The materials have been improved based upon the feedback received. A

new induction module was also developed to meet the needs of new care staff.

- Three further training events were delivered specifically for domiciliary care providers. The focus was on the implications of the MCA for day to day practice and end of life care. The events were positively received by providers.
 - The Provider Implementation Managers ran workshops, delivered presentations and participated in question panels at national conferences
 - Work to develop a guide to MCA compliance in care plans is ongoing
 - A Mental Capacity Act toolkit has been developed to support providers of social care. This includes guidance and a self audit tool so that providers can review their own performance and development action plans to support improvement. At the time of writing these documents are about to be circulated to the sector for their comments and feedback before publication.
- 5. As part of a broader programme of work on safeguarding adults, SCIE will develop resources to help local authorities commission care homes which provide safe, abuse-free services to all, including people with dementia.**

Progress:

- **Safeguarding and quality in commissioning care homes** was published in February, and provides a framework for commissioners to use to check all safeguarding issues when commissioning care homes
 - **Commissioning care homes: Common safeguarding challenges** was published at the same time, providing commissioners and providers with information about the issues that most often result in safeguarding referrals from care homes
 - Work is ongoing on a guide to using mediation and family group conferencing in adult safeguarding practice, including where the individual may lack capacity.
- 6. SCIE will work with NICE to pilot the development of a social care quality standard on the care of people with dementia**

Progress:

- Work has continued on the development of this pilot quality standard, including attending the 2nd topic expert group meeting.
- 7. As part of our programme of work on participation, SCIE will 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:

- A report and At a Glance summary of this work will be published in June.

- The participation of older people with high support needs will also be addressed as part of the development of our new Co-Production Network

Social Care Workforce Research Unit, King's College London

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

1. Our commitment to exploring and improving services for marginalized groups continues; for example, we are currently due to begin a project in June 2012 exploring the service needs of homeless older people with dementia.
2. The SCWRU User and Carer Advisory Group currently includes one current carer of a family member with dementia and three former carers. We remain committed to engaging with people with dementia and carers in designing, planning and executing our research projects. We asked our Advisory Group about the best way to engage sensitively with people with dementia and sustain their involvement without putting unnecessary pressure on them. Members of our Advisory Group gave us some valuable suggestions, and discussed the importance of trust in research relationships with people with dementia and carers. As a consequence, three members of our group who already have links with dementia cafes and other support networks for people with dementia and carers have volunteered to act as go-betweens for us. These three members will, when the need arises, be briefed on any queries we are grappling with, discuss it with their network, and report back what their network has advised.
3. For every project, we will continue to enable people with dementia and carers to contribute their views without necessarily attending meetings. This will take the form of emails with specific questions that they can respond to at their own time and convenience. We will explore other virtual methods to involve people with dementia. However, we will continue to meet support costs for people with dementia and carers who are able to come to meetings as part of our practice of reimbursement of expenses.
4. We will address the prevailing stigma and fear of dementia amongst the public in our research, through selection of research topics and question selection within individual studies, analysis, writing and dissemination activities in order that negative perceptions of dementia are not fostered by alarmist depictions of the condition.
5. We will aim to inform policy by continuing to liaise with the Alzheimer's Society in the development and delivery of its policy agenda. We will seek links with the Alzheimer's Society's Research Network (a group of 200 people with dementia, carers and former carers) if appropriate. This will enable us to scope out a wide a range of advice, as well as prevent us from 'reinventing the wheel', and wasting precious resources of time.

6. We will actively engage with partners and providers in health and social care in order that effective research is carried out in everyday contexts. Findings and implications may then be more easily transferable.
7. We will aim to produce training-relevant outputs, where feasible, from our research studies, to equip the health and social care workforce to be dementia-aware and dementia-ready. By publishing in the 'trade' press, we aim to disseminate findings of our research findings to those in everyday practice as far as possible.
8. We will expand our team by developing a social care economics work stream to enable us to evaluate and investigate elements of social care systems that are cost-effective and equitable.
9. We will actively engage with the public through social media, in the form of tweets and a Facebook presence, keeping our website up-to-date and updates on relevant blogs and forums, in addition to traditional press releases. We see this as an important way to engage with the growing numbers of the public interested in this research topic, and a potentially important strategy to achieve greater impact from our work.

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1. We are in the process of signing the relevant contracts.
- 2 - 8. Ongoing – nothing to report as yet.
9. We have successfully set up a Twitter account that reports on newsworthy events and issues in health and social care. We are awaiting King's College approval to setting up a blog which is scheduled for June 2012.

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.

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Nothing to report for this quarter

The Good Care Group

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

- We believe we are attracting and recruiting the very best professional carers through a robust recruitment and selection strategy; offering market leading packages which recognise care work as a valued profession.
- We have adopted The SPECAL Method of care for people with dementia, developed by the Contented Dementia Trust. The SPECAL Method has been shown to increase wellbeing, reduce the need for medications and enable people with dementia to stay at home for longer. The SPECAL Method is a model of care which provides a blue print for a contented life, promoting sustainable 24 hour wellbeing every day for life. This methodology starts with an understanding of dementia from the perspective of the person living with it, and suggests simple strategies which can be employed by family or professional care givers to reduce anxiety and promote wellbeing for the person with dementia. We have found this method to be both cost effective and extremely accessible to our staff
- We continue to monitor usage of antipsychotic medications in our organisations, and ensure that where a risk has been identified, we use psycho-social techniques to support people displaying distressed reactions. We believe that antipsychotics should always be a last resort.
- We provide robust training for our staff – with dedicated mandatory induction training in dementia care, as well as advanced options for carers who wish to specialise. We offer all carers the chance to embark on an advanced apprenticeship in health and social care, specialising in dementia care. All of our care delivery managers are undertaking a 12 month course in the SPECAL Method, to ensure they are equipped to full support staff and clients. We have run 3 advanced dementia skills workshops year to date, and these are proving both popular, and also enabling carers to develop new strategies to support their clients.
- We ensure that our staff team is fully supported, despite the challenges of managing a disparate workforce. We have dedicated Care Delivery Managers to support and supervise our carers, and be responsible for the delivery of high quality care to clients. We will ensure that staff have access to technology which enables easy two way communication and contact when in the field. We have a 24/7 manned service centre, and have recently promoted 10 of our most gifted

carers to the role of Senior Professional Carer. Their job is to mentor and coach other carers in the field.

- We continue to actively measure and evaluate our performance against agreed targets including client wellbeing, family stress, carer motivation and commercial viability. We seek feedback, regularly reviewing our service, and develop improvement plans based on what our clients tell us. We are currently involved in the Number 10 Transparency Initiative, setting the standards for the monitoring and regulation of care.
- We continue to build links with external parties, ensuring that we not only share our own ideas and successes, but also are able to leverage the expertise of others

Second Quarterly Progress Report 2012

Nothing to report for this quarter (new member).

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

Second Quarterly Progress Report 2012

Nothing to report for this 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.

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We continue to focus on issues affecting people who have both dementia and sight loss and the prevalence of concurrence because of their links with ageing.

As a sight loss charity an important method in our work is to support other organisations through information, expertise and research findings related to the concurrence of these conditions.

- We worked with SCIE and ARUP to host a consultation meeting about the issues that face people who have dementia and sensory impairment at the end of their life and how care and support services may ensure effective responses to their needs and those of their family and carers. The report of the meeting is available at:

http://www.scie.org.uk/news/events/previousevents/files/dementia_eol_care_event_report.pdf

The partners will work together to address recommendations from this event.

- We contributed to work by SCIE to integrate information about sensory impairment in the Dementia Gateway.
- We supported the College of Optometrists' proposals for major new research about the prevalence of different eye conditions among people with dementia and appropriate eye examinations for people with dementia.
- We informed the Housing and Dementia Research Consortium's work to develop proposals for research about how extra care housing can support people with concurrent dementia and sight loss.
- We continue to play an active role in the Vision 2020 UK Dementia and Sight Loss Interest Group. We worked with members to respond to enquiries about diagnostic techniques for dementia among people with sight loss, provision of support for meaningful occupation and access to appropriate services.

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

Second Quarterly Progress Report 2012

We will rely increasingly on electronic communication

Launched the architect designed on line virtual dementia friendly home where anyone can click on our website at <http://dementia.stir.ac.uk/virtualhome> with three thousand visitors on the first day.

We will expand our team and our range of services to match the need of providers of dementia care

- Interviewed new research professor in Dementia Studies
- Advertised for senior lecturer
- Got funding for two new posts to undertake training/consultancy/change management (to be advertised in the next few weeks)
- Recruited six new associate staff on part time contracts (with clinical and social care backgrounds) to deliver our training programmes

We will increase our research input to the courses and books that we provide

- New research based book on acute hospital design for people with dementia published
- New book on dementia friendly interior design
- Programme of research commissioned into dementia friendly communities
- New evidence based booklet produced for GPs on how to support carers

- Design audit tool for acute hospitals (at the printer!)
- New Acute Hospital Resource Pack for staff caring for people with dementia (at the printer) including DVD and poster

We will increasingly provide our services free at the point of delivery.

- New funding from charitable sources for our work gathered over this time
- “Ten Helpful Hints” days for carers of people with dementia provided free
- Continuation of free on line library and information service including free downloadable materials
- 120 students have now completed our free distance learning on line 12 week degree module “Transitions” which informs on how to support carers
- Free information provision at RCN congress, including packs with materials on dementia and incontinence and non-pharmacological responses to disturbing behaviour

Vitalise

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

- At present we have 3 centres located in Southport, Chigwell and Southampton. In 2011 we provided 219 breaks for individuals with dementia and their carers. Due to an increased demand for our service, we have created additional Alzheimer weeks and are therefore set to double this figure. In line with delivering better outcomes for people with dementia and their carers, we intend to increase the number of centres that we have and consequently the number of Alzheimer weeks that we provide. An increase in the number of centres will ensure that we are geographically placed to enable more individuals to access our centres.
- An increase in the number of centres will enable us to lower the average cost of our breaks, enabling us to further increase the subsidy for our dementia and Alzheimer weeks.
- Vitalise are keen to work in partnership with external organisations in order to deliver better outcomes for people with dementia and their carers.
- We aim to create awareness, centred on the idea of understanding dementia through campaigns and marketing initiatives.
- Vitalise intend to connect with GPs, supporting the need to identify and support carers.
- We endeavour to develop the support we offer to people with dementia and their carers, incorporating findings from research that will improve the quality and value of their break.
- We strive to contribute to dementia research through the use of surveys and guest questionnaires, detailing preferences and individual experiences.

Second Quarterly Progress Report 2012

- We have been working with the Alzheimer's Society on a local level, in order to identify guests that require respite care with financial assistance. We were successful in funding 20 guests, allocating a total of £19,800 from our discretionary fund.
- We recognise that a large number of individuals with dementia and their carers are unaware of the respite care services available to them. As a result of this, we are in the process of creating our first ever brochure specific to those with dementia. This will be available from June 2012.
- This year Vitalise has focused more on its contribution to improving the quality of life for those guests with dementia and their carers. Subsequently this quarter the fundraising team achieved a 98% increase from the first quarter figures achieved in 2011. The team have therefore already raised 72% of the total 2011 yearend sum.

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.

Second Quarterly Progress Report 2012

Nothing to report for this quarter

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

Second Quarterly Progress Report 2012

Nothing to report for this quarter