

Dementia Action Alliance



Board Paper – 15th April 2014

This is a report prepared for the Dementia Action Alliance Board ahead of their meeting on 15th April. It provides an update on progress made against the DAA Strategy since February 2014 and outlines some of the decisions to be made by the Board.

It includes monies committed to the Alliance for 2013/14 from the members and projected costs.

Creating a Board to guide the work of the Alliance

What was said in the Strategy

A Board will be formed to guide the work of the Alliance. It will include two permanent members, six elected members and four invited individuals to provide clinical expertise and experience of living with dementia and caring for someone with dementia.

April 2014 update

The National DAA Secretariat will be giving a personal thank you gift to Sharon Blackburn at the next Quarterly Meeting in recognition of her hard work co-chairing the National DAA.

Building the network

What was said in the Strategy

The Alliance will continue to grow. Membership is expected to reach 680 members by 2015: comprising approximately 180 national members and 500 local members.

April 2014 update

There are approximately 1,210 members of the Dementia Action Alliance. Of these, 171 are national members and 1,039 are local members.

Enhancing member work

What was said in the Strategy

Alliance staff will continue to enhance the impact of member actions through encouraging information sharing, providing an active 'dating service', promoting collaboration, and suggesting actions.

April 2014 update

A 'member league' table with a composite score of member updates, attendance, financial / non-financial contributions and involvement in joint work has been produced. The paper is attached to this document.

Issues to resolve

- Approval / amending / rejection of the Member League proposal (attached)

Board response 15/04/2014
1. Decision – The DAA Board decided not to use leagues tables to monitor member activity. The DAA Secretariat are to call all national DAA members, starting with the least active, to offer up support.
Reason: The ethos of the DAA is carrot and not all members have the same capacity to support DAA work.
Action: The DAA Secretariat will attempt to call all DAA members over the next 6 months, starting with the least active. It was agreed that national members would be expected to have advanced on the delivery of their commitments over the past year or could expect to have their membership reviewed.

Delivering joint work

What was said in the Strategy

Between 2012 and 2015 the Alliance will conduct on-going programmes of joint work that will be funded externally. This will include the Right Care, post diagnosis care pathway Action Group and the Carers Call to Action.

April 2014 update

Right Care

During February the National DAA Secretariat conducted a survey of Right Care members. On the 17th March they presented the results to a roundtable of senior clinicians, policymakers and researchers from NHS England, Royal College Nursing, Royal College of Psychiatry, Kings Fund, Care Quality Commission and the Department of Health.

96 clinicians, managers and chief executives completed the survey. The key findings were positive with the majority stating that improvements had been made because of the call.

Key findings:

- 84% report that a definition of a dementia-friendly hospital is necessary
- 86% of hospital trusts would pay £1,000 for an enhanced package of support
- 35% of hospital trusts claim to already be 70% dementia-friendly
- 85% report committing to become dementia-friendly made a difference to their trust
- 98% report senior managers at their hospital are still committed to becoming dementia-friendly
- 73% report increased staffing resources for improving dementia care
- 29% report reduced delayed discharge of people with dementia
- 61% report improvements in the quality of discharge of people with dementia
- 51% report already having individualised care plans for people with dementia
- 80% report increased spend on dementia friendly wards

In response to the findings, the group agreed to collectively produce **broad principles of what constitutes a dementia-friendly hospital**. The National DAA Secretariat will be conducting follow-up interviews with Right Care members to get further details on the needs of the brief and what support will be needed to implement the principals.

The telephone interviews will be taking place during late April and May. The broad principals will be produced by the group over the summer. In the meantime Right Care members will continue to be invited to DAA Webinars. A select number of Right Care members have also been invited to the May Quarterly Meeting on dementia-friendly environments. Given the large venue, this hasn't displaced any national members.

Issues to resolve

- Should the DAA coordinate members to produce an enhanced package of support?
- Should the DAA charge £1,000 to access this package of support?

Board response 15/04/2014

2. Decision – The DAA Board approved the recruitment of a DAA Right Care Officer to work up a programme of support for hospital trusts.

Reason: The Right Care has had a huge success in signing up hospital trusts. The survey results

indicate that sign up has resulted in improvements on the ground and that hospitals are willing to pay £1,000 for additional support.

Action: Dawn Brooker and Karen Harrison Denning to help the DAA Secretariat to produce a project description for an initial appointment/consultant who would then work up the longer term project plan for Right Care including the job description for the on-going Right Care Officer.

Local Dementia Action Alliance Programme

There are now 83 Local Dementia Action Alliances each with its own dedicated website page on the DAA website.

Since February 2014 the focus of Secretariat support has been on:

- Amending the Local DAA papers to remove reference to the DAA as a franchise and to strengthen the description of the Alzheimer's Society as the Accountable Body for dementia-friendly communities
- Proactive work from the Carers Call to Action Coordinator to engage Local DAAs in the call.
- Working with the DAA Local Representatives and Alzheimer's Society staff working on Local Dementia Action Alliances to conduct a Strengths, Weakness, Opportunities and Threats Analysis on LDAA activity (found in Annex 2).

Issues to resolve

- The DAA Board to form a subgroup to promote the sustainability of Local Dementia Action Alliances

Board response 15/04/2014

2. Decision – The DAA Board approved the formation of a subgroup of Peter Watson, Heather Gilling, National DAA Secretariat and Alzheimer's Society operations staff to ensure the future sustainability of local DAAs.

Reason: Local DAAs have been a major source of growth for the DAA overall. Department of Health funding which was used to establish them are also due to end in March 2015.

Action: The subgroup will report back to the Board in 6 months.

Communication Discussion Paper

In November 2013, Communication Contractor Steve Crabb drafted a Communication Discussion Paper (described as Strategy) that was submitted to the Board following the Annual Event. The Paper was based on a consultation with a number of DAA members and was formally presented to the Board on the 19th February. It sets out how the DAA will deliver communications going forward.

April 2014 update

- The external communication ambition of the DAA has been reduced and will focus on the promotion of the Calls to Action and Annual Event and providing reactive comments on the DAA itself. The scales of this support should be reflected in the staffing options discussed below.

Public Affairs around local and general elections

The public affairs role of the Dementia Action Alliance was announced at the September Quarterly Meeting including the Board's proposal that the Alliance should focus on post-diagnostic support and the postcode lottery.

April 2014 update

- The National DAA Secretariat has invited health and social care manifesto drafters from the main political parties to roundtables in early September. We are still awaiting a response from their teams.
- The National DAA Secretariat have spoken with the University of Worcester study team to draft two 'four years on surveys' of DAA members and people with dementia and carers. The study team are drafting up the surveys in late April. A copy circulated to members at the Quarterly Meeting on the 6th May. Key dissemination partners in the Department of Health, Care Quality Commission, Barchester, Bupa, Four Seasons, Age UK and Local Government Association have been notified and will be feeding comments / requirements to the study team ahead of the drafting.

Issues to resolve

- DAA Board to form a sub-group to approve the final surveys before they are disseminated

Board response 15/04/2014
3. Decision – members leading on dissemination will provide comment on redrafted but final signoff will sit with Worcester University and the DAA Board
Reason: The DAA Survey must have a wide sense of ownership but remain focused and meaningful.
Action: Worcester University will redraft the survey and circulate it to the dissemination leads for comments. The survey will be announced to the wider membership at the Quarterly Meeting in May 2014.

Carers Call to Action

The Carers Call to Action (CC2A) was launched at the Annual Event on 20th November. The 'ask' is for Health and Wellbeing Boards (HWB) to sign-up to the shared vision of the call by the end of March 2014. All HWBs have been approached through Twitter and inclusion in the Local Government Association newsletter.

An event has been scheduled for the 10th September at the Local Government Association to engage HWB's and their members in the CC2A. The day will cover nationwide good practice in supporting carers and gain feedback on the practicality of implementing it.

A booklet is also currently being produced by the CC2A, bringing together and building on existing member content to highlight to family carers their human rights and how to ask for better services.

Financially the CC2A has raised £67,300 over two and a half years (in addition to substantial in kind support from the National DAA Secretariat). These monies have been used to employ as part time CC2A Coordinator (focus organisations) and part time CC2A Carer Coordinator (focus carers) along with collateral.

Outcome indicators

What was said in the Strategy

The Alliance will work closely with the Alzheimer's Society to continue to develop their Dementia Report, which collects statistics against the outcomes of the Declaration, and use it to monitor the progress of the Alliance.

April 2014 update

The ICF GHK have been liaising with the DAA National Secretariat to ensure that the Dementia Atlas indicators are incorporated into DAA progress indicators. These indicators will be updated again in October with new outcomes from the Frail Older Person Strategy and Public Health England. The National DAA Secretariat have been in conversations with a data analysis company about collating the indicators into a coherent package that can be used by local and national members.

Alliance Events

What was said in the Strategy

Quarterly meetings will remain primarily for national members and the Annual Event will be formalised as the place where local and national members meet.

April 2014 update

The next Quarterly Meeting will be on 6th May and will cover dementia-friendly environments. The day will include input from Stirling University, Pozzoni Architects, University of Salford and front-line practitioners.

The day is over-subscribed with 115 registering for a 96 capacity room. The DAA Secretariat will be asking all the speakers to run webinars in the months following the meeting to allow members who are unable to attend to also hear about their work.

Staffing

What was said in the Strategy

The Strategy specified that during 2014/15 a Policy Manager/Officer or Senior Clinician would be seconded in to the DAA to draft a new Dementia Action Alliance Strategy.

April 2014 update

Resources

In line with the DAA Strategy there will be increased resources available for staffing in 2014/15. In 2014/15 the DAA is to receive an additional £59,200 for Local DAA activity (broken down below). Public Health England has also requested that the DAA provides output data on its DAA Secretariat Network as part of its £5,000 contribution.

Records kept by the Alzheimer's Society Finance team indicate that the National DAA Secretariat will achieve a surplus of £49,013 (excluding surpluses achieved for the Carers Call to Action). The Right Care survey also suggests that 86% of hospital trusts would pay £1,000 for an enhanced package of support. That would unlock up to £120k of money for the DAA.

Current situation

In terms of current staffing, since the departure of the Communication Adviser in May 2013 the National DAA Secretariat has focused its resources on developing the website, employing a part time contractor to maintain and develop it. This was partly due to the contentious nature of external communications and the fact that the website has become the key vehicle through which the DAA Board supports and directs the DAA movement. A limited communication budget has been spent on promoting the Carers Call to Action, the DAA Annual Event and drafting a communication discussion paper.

Capacity issues going forward

Since May 2013 there has been significant growth in the use and support requirements of the website. Unique monthly visitors have risen 65% to 5,690 over the last year. Time needed to induct members is also increasing - between March and December 2013 the DAA signed up an average of 67 new members a month, from January to March 2014 the number of members increased by an average of 200 a month. Despite an online sign-up form, each of these action plans need to be centrally vetted and/or forward across by the National DAA Secretariat. There is also an increase amount of content and online resources that need to be curated and updated, including those for the Carers Call to Action.

In 2014/15 the DAA will also be enhancing its offer to members. This includes running a monthly webinar programme, organising manifesto round tables, providing substantial in-kind support to the Carers Call to Action (approx. 1 day per week per team member) and conducting a ‘four years on from National Dementia Declaration’ survey.

Issues to resolve

Ahead of the new financial year in June the DAA Board must discuss and approve options going forward for how this resources and capacity challenges can be met. Options identified by the DAA Secretariat include:

- Create a full time **Digital and Local DAA Officer** and to cover digital media and coordinate local DAA support activity including DAA Coordinator induction, guidance note production and fortnightly DAA Coordinator calls (fulfils LDAA funding requirement)– approx. cost £35,376
- Create a part time **DAA Right Care Officer** to develop ‘service’ for Right Care members (could be sustained by Right Care member contribution) – approx. cost £17,688
- Increase days of **Communication Contractor** to promote the work of the DAA (part of core offer to members who contribute) – approx. cost £2-15,000

A full financial breakdown of staff costs will be provided to the DAA Board members following validation of figures by the Treasurer. Draft figures on how these might add up are provided in the Table 1 below.

Table 1: Staffing structure options

What the Strategy said 2014/15	Current staffing 2013/14	Proposed structure 2014/15
DAA Executive lead (FT)	DAA Executive lead (FT)	DAA Executive lead (FT)
DAA Engagement Officer (FT)	DAA Engagement Officer (FT)	DAA Engagement Officer (FT)
DAA Communication Advisor (PT)	Website Contractor (PT)	Digital and Local DAA Officer (FT)
	Communication Contractor (PT)	Communication Contractor (PT)
DAA Assistant (PT)	DAA Assistant (PT)	DAA Assistant (PT)
DAA Policy Manager	None	DAA Right Care Officer (PT)
Total cost £124,640.30	Total cost: £106,247.43	Total cost: £161,253.00
Expected to raise: £174.550	Total raised ¹ : £152,950	Expected to raise: £188,150 ²

¹ Subject to validation from Treasurer

² Based on continued turnover of £152,950 + £35,200 from Local Dementia Action Alliance Programme for Local DAA support

Board response 15/04/2014

4. Decision – the DAA Board approved the creation and DAA Digital and Local Alliance Officer and DAA Right Care Officer. The former job description and title will be signed off by Heather Gilling and the latter by Karen Harrison-Denning and Dawn Brooker.

Reason: The increased activity of the DAA has placed more pressure on the National DAA Secretariat. The new roles will allow the National Secretariat to better support local DAAs and to build on the success of the website.

Action: The National DAA Secretariat will draft up job descriptions for the respective Board members to approve.

Income and expenditure

What was said in the Strategy

Alliance income is expected to rise from **£124,625** in 2011/12 to **£174,550** in 2014/15 through modest growth of national membership (DAA financial years run from July to June).

Alliance expenditure is expected to rise from **£126,686.72** in **2011/12** to **£181,706** in **2014/15** to fund an increased core staff team, larger annual event and dedicated website budget.

April 2014 update

The Dementia Action Alliance has so far raised commitments for the 2013/14 financial year of **£169,170** for core costs and an additional **£29,030** for the Carers Call to Action. DAA core costs for 2013/14 are expected to come in at **£120,157** for core costs and **£12,567** for Carers Call to Action. These figures have been produced by the Alzheimer's Society finance team. They predict a combined surplus of **£65,476**.

From April 2014 to March 2015 the DAA will also be able to draw down an additional **£59,200** from the Local Dementia Action Alliance Programme to support LDAA activity. The support breaks down as **£19,200** for guidance note production, **£18,000** for carer engagement, **£9,000** for the Annual Event, **£6,000** for DAA wide website development and maintenance, **£5,000** for DAA wide marketing and publicity and **£2,000** Annual Report.

Previous records produced by the Alzheimer's Society finance team indicate that the DAA had previously 'banked' a surplus **£62,621** from July 2011 to June 2013.

The interim accounts will be presented to the DAA Board on Tuesday 15th April.

Issues to resolve

- Financial action points prior to next board meeting to be agreed.

Board response 15/04/2014

5. Decision – the DAA Board approved the interim accounts provided by the Alzheimer's Society Finance Team. They also requested a full breakdown of the re-profiling of National DAA costs to the LDAA Programme for 2013/14.

Reason: The DAA Board need a full grasp of the underlining running costs of the DAA.

Action: The DAA Treasury and National DAA Secretariat will draft up a project budget for next year and include re-profiled costs in end of year accounts.

Annex 1: Dementia Action Alliance Strategy Summary

Goal - 2015 and beyond

The Dementia Action Alliance becomes the hub of the health and social care element of the dementia sector. When the current phase of the Prime Minister's Challenge on Dementia ends in March 2015, members will co-produce priorities for this element of the sector and initiate joint programmes of work to fulfil them.

Route to achieving this:

Creating a Board to guide the work of the Alliance

It will include two resident members, six elected members and four invited individuals to provide clinical expertise and experience of living with dementia and caring for someone with dementia.

Building the network

The Alliance will continue to grow. Membership is expected to reach 680 members by 2015: comprising approximately 180 national members and 500 local members.

Enhancing member work

Alliance staff will continue to enhance the impact of member actions through encouraging information sharing, providing an active 'dating service', promoting collaboration, and suggesting actions.

Delivering joint work

Between 2012 and 2015 the Alliance will conduct an on-going programme of joint work that will be funded externally. This will include the Right Care, Early diagnosis and post diagnosis care pathway Action Group and the Carers Call to Action.

Outcome indicators

The Alliance will work closely with the Alzheimer's Society to continue to develop their Dementia Report, which collects statistics against the outcomes of the Declaration and use it to monitor the progress of the Alliance.

Alliance Events

Quarterly meetings will remain primarily for national members and the Annual Event will be formalised as the place where local and national members meet.

Staffing

The Alliance core staff team is to be increased by one full time equivalent post, bringing in external communication expertise to promote member work and freeing up capacity to initiate further areas of joint work (business case included below).

The Alzheimer's Society has agreed to continue hosting the Alliance core staff team for the next four years.

Income and expenditure

Alliance expenditure is expected to rise from **£126,687** in **2011/12** to **£171,705** in **2014/15** to fund an increased core staff team, larger annual event and dedicated website budget.

Alliance income is expected to rise from **£124,625** in **2011/12** to **£174,550** in **2014/15**.

Annex 2: Local and National Dementia Action Alliance SWOT Analysis

The Strengths, Weaknesses, Opportunities and Threat (SWOT) Analysis below was produced at a LDAA Sustainability Away Day on the 28th March. Attendees included the DAA Local Board rep, National DAA Secretariat, Yorkshire and Humber LDAA Chair, Regional Project Managers from North West and Yorkshire and Humber, DAA Coordinator from West Midlands, the Trusts Team, Dementia Friendly Communities Programme Manager and Operations Staff in the South West.

The analysis adds value to previous papers setting out the concept of the LDAA programme by giving a snap shot of implementation and context going forward.

Strengths

Implementation

- **Massive sign up and action.** The LDAA programme has signed up over 1,000 members organisations, within 81 local alliances who have committed to almost 4,000 actions.
- **Genuine local ownership.** Local Authorities and other charities are getting on board, taking collective ownership through chairing / funding.
- **Spread of members.** Diverse members including police forces, retailers and transport providers – not just usual suspect banging drum.
- **Grass roots growth.** LDAAs set their own agenda allowing local freedom within a national framework.
- **LDAAs in demand.** Invited to meetings, not banging down the door
- **Regional coverage.** In Regions with LDAA teams, LDAAs set up across the region.
- **Effective line management by Operation.** Regional Operations Managers have an effective overview of all Alzheimer's staff in regions.

Impact

- **Anecdotally LDAAs are delivering tangible benefits.** Estimated 30-40,000 people receiving training in Yorkshire and Humber due to LDAA members.
- **Inclusion.** People with dementia/ carers empowered and included.
- **Mounting evidence.** Evaluation data is building up across the country. This includes LDAA Programme Evaluation and Dementia Without Walls.
- **Raised profile of dementia.** Wide range of voices shouting for dementia has increased prominence with mental health commissioning – access health and well-being.

The approach

- **Innovative approach.** Getting competitors to work together and provide mutual support shouldn't work. Followed with interest by academics other conditions now wanting to follow the approach that we have pioneered.
- **An enormous release of energy.** Most action, even by individuals within organisations, is based on voluntarism. Given a leadership role to ex professionals.

- **DAA's are now well connected.** Also and act as connector – networks – including Chambers of Commerce, inter faith, strategic clinical networks
- **LDAA people.** Relaxed attitude to risk with significant staff autonomy has paid dividends. Recruited motivators and mavericks with community development as well as influencing skills.

Central / local relationship

- **DAA Secretariat Network.** Effective team working across DAA central and local DAAs including in coaching, mutual support, regular catch ups.
- **Toolkits/ resources.** Suite of resources produced by national and local DAA Secretariats.
- **Local intelligence / delivery of national initiatives.** Anecdotes on impact financial services protocol and Right Care.

Opportunities

- **Strong pooled skill base.** An audit of skill sets within DAA would allow these to be aggregated up.
- **Moving beyond pilot stage.** Priority is now scaling up, increasing capacity and sustainability.
- **Opportunities for continuation funding.** Through inclusion of LDAAs in local tenders, local contributions and successor pots to TSIP.
- **Increase work to challenge double stigma.** Build on existing work between Equity, Alzheimer's Society on LGBT and prison services
- **Sign up Local Authority Department.** Best value is achieved when local authority departments sign up.
- **Sign up branches of national corporates.** Strengthen involvement of national chains.

Weaknesses

Relationship with Alzheimer's Society

- **Ambiguous offer.** The Dementia-friendly communities / LDAA / Dementia Friends offer can be confusing to external stakeholders.
- **Perceived as a threat to Alzheimer's Society.** Independence of local DAAs can mean they are wrongly perceived as rivals to the Society. This results in distrust and lack of support from some central teams.
- **Lack of awareness and consistency across Directorates / Regions.** Low awareness of what DAAs can do and how they can support local services.
- **Linked to the Alzheimer's Society reputation.** Might be negative be affected by changes in prevalence rates, challenges in other programmes and big 'I am' perception.

Infrastructure

- **Website.** Well used but requires more resource to update it and should be reoriented towards local members.
- **Inconsistent pay grades and responsibilities.** DAA Coordinators and Project Managers responsibility vary across the country.
- **Regional gaps.** Particular North East and East of England.

- **No formal programme management.** Resulted in DAA Secretariat fulfilling role with support from Trust Team and Finance.
- **Capacity.** LDAs have grown beyond the ability of local teams to support them. When staff leave momentum stops.
- **Lack of national business engagement.** Challenges signing up big supermarket chains locally without national consent.

Threats

Lack of action

- **Lack of updates.** Local members don't update action plans so limited evidence of impact.
- **Local DAs become talking shops.** Getting members to include DAA work in their business plans is challenging.

Duplication / competition

- **Dementia friendly community.** Champion Groups and DFC Networks duplicate and compete with Local DAA
- **Dementia slips down the agenda.** Other conditions and issues take precedence.
- **Losing ownership of members.** Asked to pass businesses across to 23 Red.
- **Growing number of non-A.S. DAA Co-ordinators.** Gives LDAs to other organisations and reduces control of Alzheimer's Society and central national Secretariat / Board.

Recognition

- **Purple Angel and other badges.** Confuses messages and delicate balance between not endorsing and being seen to endorse.
- **Inconsistency.** Different areas have different approaches to 'Dementia Friendly Communities logo'.
- **Reputational contamination.** Discredited care homes/ agencies join LDAs to enhance reputation.

Sustainability

- **Local recourse.** Members have the expectations that its free.
- Contracts are short term and risk increasing turnover
- **Alzheimer's Society ends support.** Terminates hosting or creates alternative structure.
- **Dependency on volunteers.** Local DAs led by unpaid chairs.
- Bringing on board other organisations
- **Disconnect.** Decision-makers shielded from real life experience of people affected by dementia.
- **Hard to measure impact.** Impact anecdotal and lack of outcome data to chart impact.
- **Lack of legitimacy.** No formal management relationship between Local DAA Coordinators and Project Managers and the DAA Board.

