

Dementia Action Alliance Progress report and Board meeting notes - 22nd April 2013

This report is a combination of the paper prepared for the Dementia Action Alliance Board meeting on the 22nd April and the response of the Board to the issues raised within it (Board additions in blue). It provides an update on the progress made against the DAA Strategy since November, outlines decisions made by the Board and identifies actions going forward.

It also contains draft terms of reference for the Board, which was approved with amendments.

Details

The first Board meeting of the Dementia Action Alliance was held on the 22nd April at Bupa House, London from 5 - 7pm.

Board member attendees were:

- Prof Dawn Brooker – Worcester University – Research representative
- Gill Ayling – Department of Health – Statutory sector representative – dialling in
- Prof Graham Stokes – Bupa – Private sector representative
- Jeremy Hughes – Alzheimer’s Society – Not for profit sector representative and host organisation
- Peter Dunlop – Person living with dementia representative
- Peter Ashley – Person living with dementia sitting in an observational capacity
- Peter Watson – Carer representative
- Sharon Blackburn – National Care Forum – Not for profit sector representative

Alliance staff attendees:

- Sarah Gillam – DAA Communication Adviser
- Simon Kitchen – Stakeholder Relations Manager
- Sarah Tilsed – Stakeholder Relations Assistant

The meeting was Chaired and hosted by Bupa’s Prof Graham Stokes.

Creating a Board to guide the work of the Alliance

What was said in the Strategy

A Board will form 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 2013 update

The DAA Board met for the first time on 22nd April 2013. The list of initial attendees are listed on the previous page.

The initial Board members are:

- Dawn Brooker – Worcester University
- Gill Ayling – Department of Health
- Graham Stokes – Bupa
- Jeremy Hughes – Alzheimer’s Society
- Peter Dunlop – Person living with dementia
- Peter Watson – Carer
- Sharon Blackburn – National Care Forum

Deputies

To support the elected member living with dementia, the following individuals will attend Board meetings alongside them on a rotational basis:

- Daphne Wallace - Person living with dementia
- Keith Oliver - Person living with dementia
- Peter Ashley - Person living with dementia

To support the elected carer, the following individual will attend Board meetings if the elected member is unavailable. They will attend the first Board meeting as an observer:

- Manjit Nijjar – Carer

The existing members will be joined by a senior clinician and rotating local member representatives, who will be recommended by fellow local Alliance members.

Decisions for the Board to make 22/04/13:

- Select a Local Dementia Action Alliance lead to sit on Board (see Annex 2)

Board response 22/04/2013
Decision: The Board agreed that Heather Gilling from Dementia Support South Lincolnshire and Chair of South Lincolnshire Dementia Action Alliance will be invited to attend the next Board

meeting.
Reason: The Board decided to invite her on the grounds that she had been nominated by two Alliance members and had direct experience of both providing frontline services for people with dementia and running a local Alliance. Pending her acceptance she will attend the next Board meeting. It was hoped that the other candidates could be involved in the Alliance through other routes and possibly attend future Board meetings.
Action: Alliance staff, on behalf of the Board, will follow up with other nominees to thank them for their involvement and build on their enthusiasm and interest in the Alliance.
Decision: The Board agreed that local Board members should speak on behalf of all local alliances, rather than just their own local alliance.
Reason: To strengthen the connection between the Board and Local Dementia Action Alliances by ensuring that their wide and varied perspectives are represented.
Action 1: Alliance staff to amend the Board member job descriptions to include this role and ensure that the invited member is aware of it (completed by 3 rd May).
Action 2: Alliance staff to support the Local Board member in engaging with fellow local alliance members (on going).

- Select a clinical lead to sit on Board (suggestions from Board members are welcome)

Board response 22/04/2013
Discussion: Board members discussed the purpose of having a clinical lead on the Board. It was agreed that the preferred candidate will have regular face to face contact with people with dementia, be able to speak for their profession and have a strategic overview.
Decision: The Board agreed to request recommendations from all Alliance members for a suitable clinical representative to sit on the Board.
Reason: The Board agreed that the wider membership of the Alliance should be given an opportunity to nominate a candidate.
Action 1: Alliance staff to invite wider membership to nominate clinicians to sit on the DAA Board (completed by 3 rd May).
Action 2: Alliance staff will follow up with Rachel Thompson to inform her of her nomination, confirm that she is willing to put her name forward and to thank her for her work supporting DAA to date.

- Sector types and skill sets to be covered by the remaining Board positions. Note: two co-chairs (not for profit and private sector representatives) will be up for re-election in August 2013. Should these positions be continued or amended.

Board response 22/04/2013
Decision 1: The Board agreed that a financial expert should be co-op'ed to sit on the Board to provide financial advice and guidance to the Alliance.
Reason: The Alliance has raised a substantial amount of money and it is important that the Board fulfils its fiduciary responsibilities diligently and ensures the long term financial sustainability.
Action 1: Jeremy Hughes to forward relevant National Voices job description to Alliance staff (completed by 3 rd May).
Action 2: Simon Kitchen to draft Financial Board member job description for Board to provide sign-off on. The post would be advertised on the DAA website and member networks (completed by 17 th May).
Decision 2: The Board agreed that the existing sectors represented by the co-chairs (private, public and not-for-profit) would continue to be represented on the DAA Board until wider agreement from members. Existing co-Chairs will remain in place until the Annual Event.
Reason: The Board doesn't want to change its composition without prior approval from the wider membership at the AGM.

- Approve the terms of reference for the Board.

Board response 22/04/2013
Decision: The Board approved the terms of reference based on minor amends.
Action: Alliance staff amends the terms of reference (Annex 3 with approved changes in red).

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 2013 update

There are approximately 450 members of the Dementia Action Alliance. Of these, 160 are national members and 290 are local members. The significant leap in members is primarily due to 72 NHS Trusts signing up as part of the Right Care: Creating Dementia Friendly Hospitals call to action, 89 action plans being submitted by Falmouth DAA and those submitted by the Alzheimer’s Society employed DAA Coordinators in the South West, West Midlands and East Midlands.

Of the national members, 35 (21%) contribute financially or with in kind support.

Decision for the Board to make:

Given the rapid growth of DAA membership it is important that it remains meaningful and serves to improve the lives of people living with dementia. The Alliance staff seeks the views of the Board on how the membership criteria could be tightened up.

Board response 22/04/2013
Decision: The Board agreed that the core membership requirement for the DAA is committing to and fulfilling actions. All members must therefore complete an action plan and provide regular updates.
Action 1: Alliance staff to provide the Board with regular updates on member activity and actions that have taken place (completed within a week of each Board meeting).
Action 2: Alliance staff to produce a short ‘Invite’ document to go out to prospective members. This will set out the roles and responsibilities of Alliance members and the benefits of joining and taking action to improve the lives of people with dementia (completed by 10 th May).
Action 3: Alliance staff to politely request a voluntary contribution from non-paying members (completed by 31 st May)
Action 4: Alliance staff to introduce a suggested donation for Alliance members who register for events and fail to notify Alliance staff that they won’t be going (completed after quarterly events)

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 2013 update

In March 2013 the Alliance launched a new DAA website that provides an enhanced search function for members. This will be used by members to enhance joint work and promote collaboration. Over the next two months Alliance staff will be providing training for national DAA members on how to use the website.

Board response 22/04/2013
Decision: It was agreed that the Board / Alliance staff have to approve any joint work conducted under the branding of the Dementia Action Alliance
Reason: There was concern that members will carry out work under the branding of the Dementia Action Alliance which doesn't fulfil the outcomes of the Declaration or ethos of the Alliance.

Delivering joint work

What was said in the Strategy

Between 2012 and 2015 the Alliance will conduct ongoing programmes 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.

April 2013 update

Right Care

Phase 1 is completed with 124 acute trusts signing the pledge and either joining or committing to joining the Dementia Action Alliance. The NHS Institute, that led the campaign, came to an end at the end of March 2013.

The Alliance is currently seeking funding for a Phase 2 from NHS England. Alzheimer's Society has provided £5k to Catherine Holmes Associates to continue the programme until the end of May. This intermediate phase will include a series of webinars for Acute Trusts who have signed up.

The DAA has received £12.5k to establish a Right Care LinkedIn network using the contacts gained from the Institute's National Field Network. These monies will be used to part fund the Communication Adviser role.

Right Prescription

The Right Prescription supported the 52% reduction in the use of antipsychotics. The campaign has now ended with no intention to re-establish it as an individual entity.

Alliance work to reduce antipsychotics will now be woven into the Right Care campaign and through a Right Prescription LinkedIn network, established through £12.5k and contacts from the NHS Institute. These monies will be used to part fund the Communication Adviser role.

Early diagnosis

The Early Diagnosis and Post Diagnostic Pathways Action Group received £8,500 from 2011/12 DAA surplus income to part fund, with the Department of Health, Alliance research into the benefits of early diagnosis and pilot information prescriptions to improve post diagnostic pathways.

The results from these studies are due in May and will be promoted to the wider membership of the DAA at the next quarterly meeting in June.

Carers Call to Action

The Carers Call to Action has been a regular feature at Alliance meetings. A common set of goals have now been established and a total of £10k has been committed by the Alzheimer's Society and Nutricia.

The active members will be meeting over the coming month to develop a project plan for the Call to Action.

Dementia Care and Support Compact

To support the English Community Care Association in delivering the Dementia Care and Support Compact, the Dementia Action Alliance has agreed to host the compact on its website and provide limited administrative support in processing sign-ups.

The Department of Health has provided the Alliance with £4k to fund the cost of this support.

Local Dementia Action Alliance Programme

The Alliance has supported Alzheimer's Society in developing Local Dementia Action Alliances across England. This includes producing toolkits, guidance notes and creating a central hub for Local Alliances and their members on the DAA website. There are now 23 Local Dementia Action Alliance registered on the DAA Website.

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 2013 update

In March ICF GHK were commissioned by the Alzheimer's Society to conduct a two year evaluation of the Local Dementia Action Alliance Programme. As part of the evaluation the consultants will be conducting a meta-analysis of datasets available at the national and local level to measure the impact of member activity against the National Dementia Declaration. If appropriate, these statistics will be used to measure the impact of the Alliance overall.

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 2013 update

The first quarterly meeting of 2013 has been successfully delivered and planning begun for the next quarterly and annual event. Central Hall, Westminster has been provisionally booked for the annual event, along with additional breakout space to accommodate local members. Bupa have agreed to continue sponsoring the event.

Staffing

What was said in the Strategy

The Alliance core staff team was to be increased by one full time equivalent in 2012/13 and by an additional part time equivalent in 2013/14. The principal reason for these changes was to boost the stakeholder relations team's capacity and bring in external communications and social media expertise.

April 2013 update

Three candidates were interviewed on the 3rd April with two progressing to second round interviews on the 15th April. We expect the successful candidate will be in place by the end of April. Their first priority will be to build the Right Care and Right Prescription LinkedIn networks followed by agreeing core messages for local Alliances and re-convening the Communications Steering Group.

The Alliance has also benefited from a two-month internship paid for by Vodafone.

Recruitment will begin over the summer for the part time equivalent post to provide additional administrative support to the staff team in 2013/14 as outlined in the DAA Strategy.

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 **£171,704.09** in **2014/15** to fund an increased core staff team, larger annual event and dedicated website budget.

April 2013 update

For the 2012/13 financial year, the Dementia Action Alliance has so far raised **£163,021**. Of this, £10,000 is ring-fenced for the Carers Call to Action, £25,526 for developing the LinkedIn social networks, £4,000 for staff time supporting the Dementia Care and Support Compact and £2,750 for the Vodafone internship.

Core alliance expenditure is expected to be no higher than **£131,464.70** for 2012/13 (see Annex 5). This gives should give a surplus of at least **£31,556.30** (of which £10,000 is ring fenced for the Carers Call to Action).

Decision for the Board to make:

How should the Alliance spend this surplus income?

It is proposed that the Board invites light touch proposals from the national membership of the Dementia Action Alliance for projects to fund. The projects will be judged by the Board against the following criteria:

- Contribution to delivering the National Dementia Declaration i.e. how will it improve the lives of people with dementia and those that care for them
- Credibility of the project i.e. can it be delivered
- How it promotes joint work between members i.e. how wider membership was involved in developing it / how membership will be involved in its delivery and whether it levers in existing member funding
- How the project will be a catalyst for wider change

The Board will make the final decision on which bids to fund.

Board response 22/04/2013

Decision: The Board agreed that the Alliance surplus should not be spent and be used instead to build up a reserve of at least 1/3 of annual running costs.

Reason: Maintaining a financial reserve is good practice in the charity sector and the surplus has been partially achieved through a one off payment from the NHS Institute which has now ceased to exist.

Any other business – raised and discussed at Board meeting

Given the changing health environment, the Department of Health recommended that Public Health England or NHS England would now be more suitable statutory sector representatives to sit on the DAA Board going forward.

The next Board meeting will include a discussion on how the Alliance engages with BAME communities.

Sharon Blackburn was approached by BBC/Panorama in both her DAA Co-chair and National Care Forum capacity to take part in a documentary on the prescription of antipsychotics for people with dementia. The fellow Co-Chairs and Alliance staff were approached by Sharon for advice and support on how to respond. Graham Stokes offered support and Simon Kitchen provided her with information outlining the position of the Alzheimer's Society, who had also been approached. The opportunity was raised at the meeting to get the Board's view on whether the Alliance should be involved.

Given the controversy of the subject and the potential reputational risk to Alliance members the Board agreed that the Alliance shouldn't be directly involved but that Alliance members would be invited to participate as independent organisations.

Manjit Nijjar, the deputy carer representative, was unable to attend the first Board meeting as an observer. The Board agreed that she should be invited to attend the future meeting.

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 ongoing 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).

Hosting

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 **£126,686.72** in **2011/12** to **£171,704.09** 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: Nominated Local Dementia Action Alliance Representatives

Nominee	Organisations	Nominator	Nominator Organisation	Comment
Tony Parker	Tavistock Dementia Action Alliance	Dr Geri Parlby	REPoD	Tony is the chairman of the Tavistock Dementia Action Alliance as well as the Dementia Friendly Community Co-ordinator for REPoD. He is a driving force behind the development of Rotary backed local dementia friendly communities
Heather Gilling	Dementia Support South Lincs	Tory Pearce	Alzheimer's Society	Heather is the Chair for the South Lincolnshire DAA and has personal experience of being a carer for her husband who had dementia. Heather is involved in running Dementia Support South Lincs and plays an active role in the South Lincolnshire community with a lot of networks and contacts. Heather is a very active individual who strives to create change and has been a huge asset in developing the South Lincolnshire DAA.
Heather Gilling	Dementia Support South Lincs	Ruth Baldry	Lincolnshire CVS	Good knowledge and experience of subject, knowledge and experience of DAA as chair of local group.
Dr Oliver Corrado	The Leeds Teaching Hospitals NHS Trust	Philip Norman	The Leeds Teaching Hospitals NHS Trust	Consultant Geriatrician and Trust 'Dementia Champion'

Annex 3: DAA Board Terms of reference

Dementia Action Alliance Board: - Terms of Reference

The Dementia Action Alliance is a cross-sector, England-wide body that works to radically improve the lives of people with dementia and those that care for them. It does so through gaining sign-up to the National Dementia Declaration, promoting action within member organisations and supporting the development and delivery of joint programmes of work.

Dementia Action Alliance mission

“To transform the lives of people with dementia and those that care for them through building commitment and actions to deliver the National Dementia Declaration”.

This will be achieved through:

- Building a network of organisations that are committed to, and taking, action to improve the lives of people with dementia and their carers
- Enhancing member work to improve the lives of people with dementia
- Developing and delivering joint work on common priorities
- Development and updating outcome indicators to monitor the impact of the Alliance
- Running engaging member driven events

Aim of the Dementia Action Alliance Board

The Dementia Action Alliance Board provides the overall governance and strategic direction for the Dementia Action Alliance.

Its objectives are to:

- Guide the work of the Alliance
- Maintain the independence of Alliance
- Oversee the development of Alliance priorities
- Ensure the Alliance is on a secure financial footing
- Rotate the chairing of Alliance events
- Set membership criteria
- **Approve (with Alliance staff) areas of joint work conducted under the name of the Alliance**
- Agree work plan of staff and monitor performance

Membership

The Board consists of a representative from each of the key sectors covered by the Dementia Action Alliance, of sufficient authority to speak for, and act on behalf of, their sector. It will also include people with dementia and a carer, elected by fellow DAA Affiliates¹, a senior clinician, a Local Dementia Action Alliance member (rotated around those recommended by local members) and two permanent members, the Department of Health (as a larger funder and policy lead) and Alzheimer's Society (as the second largest funder and host). **A finance expert will be co-opted on the Board to support it in upholding its fiduciary responsibilities.**

The Board will be led by two co-chairs representing both the organisational members and the DAA Affiliates. Both will be selected by consensus decision by the Board.

Decisions

The Board will normally seek to reach decisions by consensus. If consensus cannot be reached, actions may be approved by a majority of those Board members present. **A quorum shall be two thirds of the Board at the time in question.**

Meeting frequency

The Board should meet at least four times a year.

Ways of Working

Board meetings will be convened and supported by Alliance staff.

All meeting papers, including the agenda and presentations, will be circulated a week in advance.

Board members who aren't able to attend will receive copies of the paper. Any questions, points of information, or comments they wish to raise can be passed to either Alliance staff or fellow Board members. These will then be fed into discussions at the meeting.

People with dementia will also be contacted by phone in advance of meetings to go through papers verbally.

There will be occasions when the Board is required to make decisions between Board meetings. In these circumstances, Board members will be contacted by email and given three days to respond with comments. A decision will be made by majority voting with four board members being the minimum required to agree a decision.

¹ A holding title for people with direct experience of dementia, either through living with it or caring for someone with it.

Annex 4: Income and expenditure

Dementia Action Alliance: Table 1 costs

	Predicted 2011/12	Actual (2011/12)	Predicted 2012/13	Actual costs 2012/13	Predicted costs end 2012/13	Predicted 2013/14	Predicted 2014/15
Secretariat costs	£84,000	£70,683.60	£92,950.80	£77,986.01	£99,710.80 ²	£121,010	£124,640.30
Venue hire	£10,000	£1,785.40	£2,000.00		£0.00	£2,060.00	£2,121.80
Accommodation and travel for people with dementia and carers	£5,000	£4,200.72	£5,000.00	£3,409.24	£5,000.00	£5,150.00	£5,304.50
An Annual Report	£2,000	£3,000	£3,090	£2,591.90	£2,591.90	£3,182.70	£3,278.18
An Annual Event	£6,000	£13,149.00	£13,500.00	£16,424.00	£16,424.00	£25,000.00	£25,750.00
Website development	£3,000	£25,368.00	£10,000.00	£7,738.00	£7,738.00 ³	£10,300	£10,609.00
Early diagnosis:		£8,500					
Total Budget	£110,000	£126,686.72	£126,540.80	£108,149.15	£131,464.70	£166,703.00	£171,704.09

² Increasing staffing cost from Stakeholder Relations Assistant going full time, Comms Adviser, Vodafone internship and extra capacity required to support the Dementia Care and Support Compact.

³ Purchasing web-ex for Right Care / Right Prescription LinkedIn networks and £5,000 contingency for changes to website