

# DEMENTIA ACTION ALLIANCE



## GOVERNANCE FRAMEWORK

Managing our mission to transform the  
lives of people with dementia and  
those that care for them

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## Introduction

This document provides an overview of the background, working and governance of the Dementia Action Alliance. The document will be reviewed following each Annual Meeting in order to ensure currency.

## The Dementia Action Alliance

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.

The mission of the Alliance is:

“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 is 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
- Developing and updating outcome indicators to monitor the impact of the Alliance
- Running engaging member driven events.

## Perpetual Outcome Indicators

The Alliance works closely with the Alzheimer’s Society in the continued development of their Annual Dementia Report. This collects statistics against outcomes of the Declaration and will be used to monitor progress of the Alliance.

## Brief History

The Dementia Action Alliance was set up in 2010 to bring about radical changes in the way society responds to dementia and to transform quality of life for people living with the condition. At the time forty one organisations from the charity, public, and private sectors came together to form a united front against dementia.

As its first act, the Dementia Action Alliance launched the National Dementia Declaration in October of 2010 at the Department of Health Conference on

Improving Dementia Care in London. The Declaration outlined seven outcomes people with dementia and their carers said they would like to see in their lives (see Appendix 1). This included having personal choice, having support to help them live their life and living in an enabling and supportive environment. As part of their pledges, member organisations also committed to ensuring their work was informed by the views of people with dementia and their carers, that they would report publically on their progress and would work in partnership with other organisations to share knowledge about best practice.

By the summer of 2013, the membership of the Alliance had increased fourteen-fold to over 600 members. Of these, 121 were national and 480 were local members. A Board was constituted in April 2013 in order to more effectively manage the development and operation of the Alliance.

## Membership

The Dementia Action Alliance has both 'national' and 'local' members.

### Criteria

'National members' of the Dementia Action Alliance are organisations that work across England or that have an aspiration to deliver better outcomes across England (and beyond if organisations work across home nation boundaries). They have to publish an Action Plan on the DAA website when they first sign up. National members of the Alliance take part in quarterly reporting and quarterly meetings at the national level and are asked to make voluntary financial or in kind contributions to the running of the national Alliance.

'Local members' of the Dementia Action Alliance are organisations that work in a specific area of England but do not have national reach. They also need to have an action plan published on the DAA website. Local members are encouraged to join together to form Local Dementia Action Alliances to deliver local outcomes for people with dementia and carers as described in the National Dementia Declaration. Local members of the Alliance take part in quarterly reporting and quarterly meetings at a local level and are invited to attend the DAA Annual Event. They may be asked to make voluntary financial or in-kind contributions to the running of their local Alliance.

### Commitments

The fundamental principle of the Dementia Action Alliance is that it is an Alliance of members undertaking Actions to improve the lives of people living with Dementia. It is important that the membership remains meaningful, serves to improve the lives

of people living with dementia, and commits to actions to achieve these aims. Therefore each member has to commit to:

- Completing an Action Plan on joining the Alliance
- Updating that Action Plan on a regular basis, preferably quarterly, but at least once a year
- Reporting on planned actions that have been undertaken and where possible the effect those actions have had.

### Membership requirements and restrictions

Any organisation that submits an Action Plan and commits to action will be considered for membership of the Alliance.

There are a number of commercial organisations in the Dementia Action Alliance and the Alliance will be looking to expand the range of commercial organisations, including pharmaceutical companies.

If any member of the Alliance has serious concerns about an organisation being a member of the Alliance they should raise the concerns with the elected Chairs. If issues cannot be resolved a small sub-group will be convened to discuss the concerns raised.

### Joint Working

Between 2012 and 2015 the Alliance will conduct an ongoing programme of joint work that will be funded externally. These areas of joint work will achieve two outcomes for the Alliance: 1) to overcome intolerable situations identified by members; and 2) to provide examples of how members can work together and the benefits of pooling resources.

Areas of joint work include:

- The Right Prescription: call to action to ensure the appropriate use of antipsychotics (delivered)
- Campaign to boost early diagnosis and post diagnosis pathways (in delivery)
- The Right Care: creating dementia friendly hospitals (in delivery)
- Carers Call to Action (development)
- Care homes (scoping)
- Party Manifestos (scoping)

Any member(s) wishing to initiate an area of joint work under the banner of the DAA must first seek approval from either the Board or the Lead Executive of the Alliance Secretariat.

### Thematic Surveys

To supplement information collected by quarterly updates, thematic surveys may be conducted by members. There will be a maximum of one per quarter. Quarterly thematic survey topics and questions are chosen by members within Action Groups and the findings used to share good practice and inform future Action Group activity.

### Use of the DAA logo

- Members of the Alliance are allowed to state in publications and e-materials that they are members of the Dementia Action Alliance and support the work of the Alliance
- When describing the work of the Alliance, members may use the Alliance logo in line with brand guidelines
- The Alliance logo will be used in relation to Alliance action when Alliance action has been agreed by the DAA Board or Alliance Secretariat
- The logo must not be used to suggest support for events of published materials where Alliance permission has not been given.

### Connecting members

#### Meeting attendance, agenda and priority setting

- All national members of the Alliance, people with dementia and carers nominated by organisations will be invited to all non-Board meetings of the Alliance
- At quarterly meetings of the national Alliance we aim to have at least 5 people with dementia and at least 5 carers
- All members of the national Alliance, people with dementia and carers are invited to submit agenda items for quarterly discussions
- Members of the national Alliance, people with dementia and carers will be invited to join agenda planning meetings prior to the quarterly meetings

- Organisations that present projects at quarterly meetings will explain the opportunity for Alliance members to benefit from the project and how they can get involved in the work
- If an Alliance member wishes to have an Alliance discussion outside of quarterly meetings, the member will alert Alliance Secretariat who will discuss how to arrange the discussion and invite members.

### Alliance Directory and Website

All national members are invited to share their contact details and update each other on their work through the Alliance Directory and Website.

### Financial Requests

Members are asked to make a voluntary contribution or equivalent in kind contribution to the running cost of the Alliance. The suggested amount is based on organisational turnover:

Turnover of up to £250,000	£250
Turnover of up to £1 million	£500
Turnover of up to £3 million	£1000
Turnover of up to £5 million	£1500
Turnover of up to £10 million	£2,000
Turnover of up to £15 million	£2,500
Turnover of up to £20 million	£3,000
Turnover of up to £25 million	£3,500
Turnover of up to £30 million	£4,000
Turnover of up to £50 million	£4,500
Turnover of over £100 million	£5,000

Funding will be accounted for in a written report to the Board, which will be shared with all members. Member contributions will also be included in the Dementia Action Alliance Annual Report which is mailed out to all national members and key opinion formers.

## Local Dementia Action Alliances

A Local Dementia Action Alliance is a collection of stakeholders brought together to improve the lives of people with dementia in their area. They typically include a range of organisations within a community for example bus companies, taxi firms, police forces, fire and rescue services, high street retailers, local authorities, charities, care providers and health trusts, faith groups, local associations or schools.

Local Dementia Action Alliances are eligible to have their own space on the DAA website and a personalised DAA logo based on the standard design. They are encouraged to work towards Dementia Friendly Communities recognition.

A Local Dementia Action Alliance can be established at any level; be it a village, a city or even a region. Alliances can overlap geographically, meaning that members are able to participate in more than one Alliance. Overlapping Alliances can develop different priorities, though if these priorities coincide then they are encouraged to develop a common programme of action.

All organisations seeking to set up a local or regional Dementia Action Alliance must first be a member of the Dementia Action Alliance. They are subject to the same membership requirements listed in the terms of reference, including signing up to the National Dementia Declaration and submitting an Action Plan using the same template.

Local and Regional Dementia Action Alliances must be inclusive of branches of national members. Local branches of national members are invited to join local Dementia Action Alliances and encouraged to submit their own action plan.

Local and Regional Dementia Action Alliances can:

- Establish local governance structure including Boards and request enhanced reporting requirements from members
- Apply for funding for joint activity that promotes the National Dementia Declaration
- Issue communication on behalf of their local or regional Dementia Action Alliance, but must consult national Alliance Communication Steering Group and/or Secretariat to ensure consistency of messages
- The interests of local Dementia Action Alliances are represented on the Board by the Local Dementia Action Alliance representative.

## Role of people affected by dementia within the DAA

The input of people with dementia and people caring for people with dementia are fundamental to the development of and implementation of actions designed for their benefit. Therefore they are encouraged to become active within the membership of the Alliance. The most effective way they can do this is by playing a part within an organisation which, as a full member of the Alliance, can represent their views.

Both people with dementia and carers are represented on the DAA Board. At quarterly meetings of the Alliance we aim to have at least 5 people with dementia and at least 5 carers. They are also actively involved in agenda drafting and priority setting for the Alliance overall, through attendance at meetings and participation in surveys.

## Management Structure

### The DAA Board

#### Purpose of the 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 the Alliance
- Oversee the development of Alliance priorities
- Rotate the chairing of Alliance events
- Set membership criteria
- Approve (with Alliance Secretariat) areas of joint work conducted under the name of the Alliance
- Agree work plan of Secretariat and monitor performance.

#### Board membership

The Board consists of individuals who have sufficient authority to speak for, and act on behalf of, the sector and people that they represent. They include:

- Representatives from the key sectors covered by the membership of the DAA
- A representative of people with dementia
- A representative of family carers
- A senior clinician
- A representative of the Local Dementia Action Alliance membership
- A financial expert to support it in upholding its fiduciary responsibilities.

Key DAA Sectors are:

- Statutory
- Private
- Not for profit (split between National Care Forum and Alzheimer's Society)
- Research.

#### Elections to the Board

##### Permanent Members

The Department of Health (as the largest funder and policy lead) and the Alzheimer's Society (as second largest funder and host) are permanent members of the Board. Their representatives are recommended from within these member organisations and voted upon for acceptance by the Board.

##### Other Key Sector Representatives

Each of the other three Key Sector representatives are nominated by and voted-upon by the national membership.

##### Person with Dementia and Family Carer Representative

The person with dementia representative is nominated and voted upon by the

community of people directly affected by dementia. They include people living with dementia and those that are / have cared for people with dementia. The list of these people is maintained by the member organisations that represent them. Nominated carers of the people with dementia will also be contacted to assist if necessary with the nomination and voting process. The elected representative is supported by a rotated deputy selected from the list of other nominated people with dementia.

### Clinical Representative

The clinical representative is nominated by national Alliance members and voted-upon by the Board using the following criteria: they have regular face to face contact with people with dementia, be able to speak on behalf of their profession and have a strategic overview.

### Representative of the Local Dementia Action Alliance membership

The local Alliance member representative speaks on behalf of all local alliances, not just their own local one. Representatives are nominated by Local Action Alliances and voted upon by the Board.

### Financial expert

To provide financial oversight of Dementia Action Alliance monies. Nominations are made by national members and voted upon by the Board.

### Election Process

Initial elections took place during March 2013 in order that the representatives could take up their role at the April 2013 Board Meeting. Each has a term of office of two years. See Appendix 2 for current list of Board Members and their term of office details. Previous co-chairs were co-opted onto the Board and are up for re-election in November 2013. Their term will only be for 18 months to bring them into line with the other elected Board members.

Should a Board member leave office within the term, the Board has the authority to institute a new election for a replacement to complete the term, institute an election for a new representative to complete the current term and serve the whole of the following term, or to co-opt a representative to serve out the remainder of the existing term.

### Board Meetings

The Board meets at least 4 times a year. Meetings are convened and supported by the Alliance Secretariat team. All meeting papers, including the agenda and presentations are circulated a week in advance.

Board Members who are unable to attend a meeting will receive copies of meeting papers. Any questions, points of information, or comments they wish to raise can be passed to the Alliance Secretariat or to fellow Board members. These are then fed into discussions at the meeting.

Alliance Secretariat contact people with dementia by phone prior to the meeting to go through the papers verbally.

## Decision Making

At Board Meetings, the Board seeks to reach decisions by consensus. If consensus cannot be reached, then actions may be approved by a majority of those Board members present. Decision cannot be taken at a Board meeting unless there is a quorum. A quorum is defined as two thirds of the Board at the time in question.

There are occasions when the Board is required to make decisions between Board meetings. In these circumstances, Board members are contacted by email and given three days to respond with comments. A decision is then made by majority voting with four Board members being the minimum required to agree a decision. The Alliance Secretariat contacts people with dementia by phone at this time to go through the issue in question verbally.

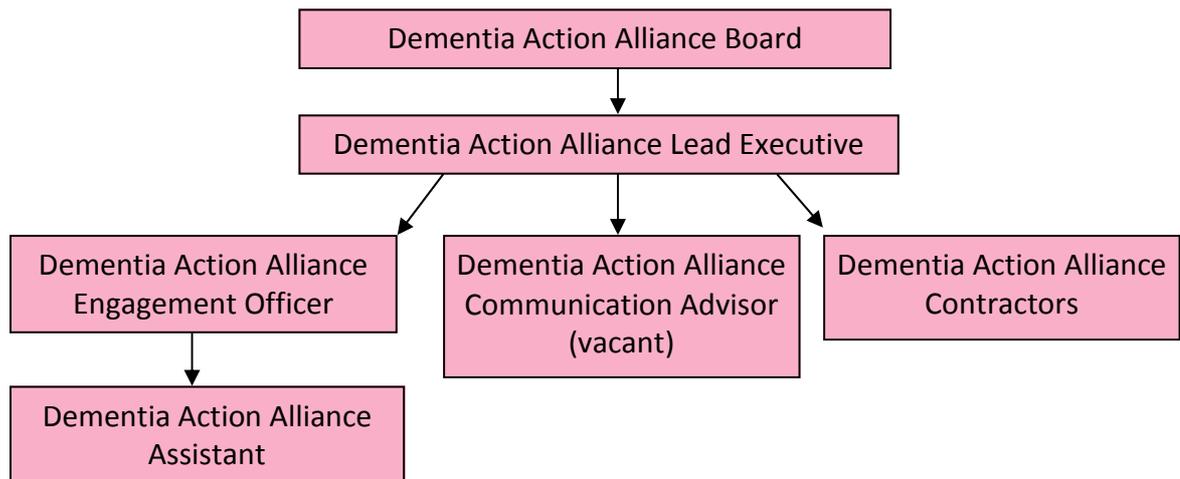
## Alliance Secretariat

### Responsibilities

The Dementia Action Alliance is supported by a core Secretariat team. They are employed by the Alzheimer's Society on behalf of the whole Alliance but report to the Board. The team are responsible for the day to day running of the Alliance, which includes:

- Being the first point of contact for the Alliance
- Accepting and inducting new national members and advising potential members on joining the Alliance and what actions to commit to
- Being the outward face of the Alliance, promoting Alliance work and member activity in the national media and trade press (alongside Board members)
- Servicing the Alliance Board (fulfilling duties outlined above)
- Organising Alliance events for national members and an Annual Event for all members
- Conducting research and policy analysis on behalf of the Alliance
- Producing /signing off Alliance outputs such as the Annual Report
- Initiating, approving and overseeing joint work between Alliance members under the DAA umbrella
- Maintaining and developing the DAA website for all Alliance members
- Maintaining a contact database of national members
- Requesting and looking after member contributions
- Spending Alliance monies within overall budget set by the Board
- Making day to day decisions needed to fulfil the responsibilities given above and achieve objectives set out in the DAA Strategy

## Structure



The full list of current Secretariat can be found in Appendix 3 below.

## Reporting

The Alliance Secretariat reports into the Board on a quarterly basis. This includes a financial and membership update and progress report on how the Alliance is fulfilling its objectives.

## Finance

The day to day running costs of the Alliance are funded through four sources:

- Direct grants
- Sponsorship
- In kind support
- Member voluntary contributions.

These monies are spent on the following items:

- Secretariat costs
- Quarterly and Annual Events
- Accommodation and travel for people with dementia and carers
- An Annual Report
- Website
- Joint work between members

## **Appendix I - National Dementia Declaration**

### **Desired outcomes for people with dementia and their carers**

People with dementia and their family carers have described seven outcomes they would like to see in their lives. There is overlap between these outcomes and the draft outcomes in the Department of Health's National Dementia Strategy Implementation Plan.

#### **1 I have personal choice and control or influence over decisions about me**

I have control over my life and support to do the things that matter to me.

I have received an early diagnosis which was sensitively communicated.

I have access to adequate resources (private and public) that enable me to choose where and how I live.

I can make decisions now about the care I want in my later life.

I will die free from pain, fear and with dignity, cared for by people who are trained and supported in high quality palliative care.

#### **2 I know that services are designed around me and my needs**

I feel supported and understood by my GP and get a physical check-up regularly without asking for it.

There are a range of services that support me with any aspect of daily living and enable me to stay at home and in my community, enjoying the best quality of life for as long as possible.

I am treated with dignity and respect whenever I need support from services.

I only go into hospital when I need to and when I get there staff understand how I can receive the best treatment so that I can leave as soon as possible.

Care home staff understand a lot about me and my disability and know what helps me cope and enjoy the best quality of life every day.

My carer can access respite care if and when they want it, along with other services that can help support them in their role.

#### **3 I have support that helps me live my life**

I can choose what support suits me best, so that I don't feel a burden.

I can access a wide range of options and opportunities for support that suits me and my needs.

I know how to get this support and I am confident it will help me.

I have information and support and I can have fun with a network of others, including people in a similar position to me.

My carer also has their own support network that suits their own needs.

#### **4 I have the knowledge and know-how to get what I need**

It's not a problem getting information and advice, including information about the range of benefits I can access to help me afford and cope with living at home.

I know where I can get the information I need when I need it, and I can digest and re-digest it in a way that suits me.

I have enough information and advice to make decisions about managing, now and in the future, as my dementia progresses.

My carer has access to further information relevant to them, and understands which benefits they are also entitled to.

## **5 I live in an enabling and supportive environment where I feel valued and understood**

I had a diagnosis very early on and, if I work, an understanding employer which means I can still work and stay connected to people in my life.

I am making a contribution which makes me feel valued and valuable.

My neighbours, friends, family and GP keep in touch and are pleased to see me.

I am listened to and have my views considered, from the point I was first worried about my memory.

The importance of helping me to sustain relationships with others is well recognised.

If I develop behaviour that challenges others, people will take time to understand why I am acting in this way and help me to try to avoid it.

My carer's role is respected and supported. They also feel valued and valuable, and neither of us feel alone.

## **6 I have a sense of belonging and of being a valued part of family, community and civic life**

I feel safe and supported in my home and in my community, which includes shops and pubs, sporting and cultural opportunities.

Neither I nor my family feel ashamed or discriminated against because I have dementia. People with whom we come into contact are helpful and supportive.

My carer and I continue to have the opportunity to develop new interests and new social networks.

It is easy for me to continue to live in my own home and I and my carer will both have the support needed for me to do this.

## **7 I know there is research going on which delivers a better life for me now and hope for the future**

I regularly read and hear about new developments in research.

I am confident that there is an increasing investment in dementia research in the UK.

I understand the growing evidence about prevention and risk reduction of dementia.

As a person living with dementia, I am asked if I want to take part in suitable clinical trials or participate in research in other ways.

I believe that research is key to improving the care I'm receiving now.

I believe that more research will mean that my children and I can look forward to a range of treatments when I need it and there will be more treatments available for their generation.

I know that with a diagnosis of dementia comes support to live well through assistive technologies as well as more traditional treatment types.

## Appendix 2 - Board Membership

The current Dementia Action Alliance Board is composed of the following people:

- Prof Dawn Brooker – Worcester University – Research representative
- Gill Ayling – Department of Health – Statutory sector representative (to be replaced following resignation)
- 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 Watson – Carer representative
- Sharon Blackburn – National Care Forum – Not for profit sector representative
- Heather Gilling—Local Dementia Action Alliance Representative
- Clinical Representative—to be confirmed
- Financial Representative—to be confirmed

### Appendix 3: Alliance Secretariat

The current roster of Alliance Secretariat is:

- DAA Lead Executive – Simon Kitchen
- DAA Engagement Officer – Sarah Tilsed
- DAA Assistant – Renee Arceo